

**NEONATAL TRAUMA: MOTHERS' PSYCHOLOGICAL MORBIDITY
AND
RESEARCH PORTFOLIO**

(PART 1)

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JULY 2000

Submitted in partial fulfillment of the degree of Doctorate in Clinical Psychology,
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A single case study

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ACKNOWLEDGEMENTS

I would like to thank Liz Campbell for her valuable input to this portfolio over the past two years. Thanks also to Christina Del Priore and Barbara Holland for their enthusiasm and interest which ensured that this research project got off the ground. I would also like to thank all my academic and clinical supervisors who have been a great help during the course.

Last, but not least, thanks to Rob for his continual support throughout my training and to “the Class of 2000” who have made the last three years so enjoyable.

SMALL SCALE SERVICE EVALUATION PROJECT

PROVIDING SERVICE INFORMATION: Do clinical psychology clients find this useful and does it affect opting in, attendance and early drop out?

Prepared for submission to *Health Bulletin*

(see Appendix 1.1 for Notes for Contributors)

PROVIDING SERVICE INFORMATION: Do clinical psychology clients find this useful and does it affect opting in, attendance and early drop out?

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ABSTRACT

Objectives: To determine whether sending prospective clients service information prior to the first appointment influences opting in to the service, first appointment attendance and early discontinuation of therapy. The study also assessed how this information was received by clients and which aspects they found to be most helpful.

Design: Two independent samples were compared. 1998 referrals received an information leaflet prior to opting in and the 1997 referrals received no written information.

Setting: A West of Scotland Clinical Psychology department.

Participants: All out-patient referrals to the psychology department (excluding neuropsychology) during a 7 week period in 1998 were compared to referrals from the same 7 week period in 1997.

Results: 36% of the questionnaires were returned, with all respondents rating the leaflet positively on a number of factors. The opt-in, attendance and early termination of therapy rates were not significantly influenced by the information leaflet, although there was a slight trend showing more people opting in and attending first appointments and less terminating therapy early. Those who returned the question sheet were significantly more likely to opt-in and attend their first appointment. People who had seen a psychologist previously did not differ on these factors from those who had not.

Conclusions: The provision of information to prospective clinical psychology clients did not significantly influence opting in, attendance or dropping out of the service, but the information leaflet was rated positively and was found to be helpful by all those who completed the question sheet.

(Word count=244)

INTRODUCTION

Non-attendance and early discontinuation of therapy

Non-attendance and early discontinuation of therapy continue to be a significant problem for clinical psychology, resulting in much wasted therapy time which could be used to treat patients on the ever-increasing waiting lists apparent in many departments today. Failure to attend appointments results in a missed opportunity for clients and, according to Hughes (1995), can result in decreased therapist morale. In the 1993 DCP survey 44% of referrals were made to departments with waiting times of at least six months. Long waiting times frustrate GPs, put pressure on psychologists and are unfair to clients. Madden and Hinks (1987) highlighted that, in their study, 17% failed to attend the first appointment, 22% had dropped out by the second appointment and 35% eventually dropped out.

Why do people fail to attend or drop out of therapy?

Munro and Blakey (1988) highlighted that the person who suggested the referral (the GP or the client) and how many times it had been discussed influenced attendance. Gerhand and Blakey (1994) suggested that clients may fail to attend or discontinue therapy prematurely because they did not actually want referral in the first place. This highlights a need for educating both GPs and patients about available services. Balfour (1986) suggested that patients fail to attend first appointments or drop out from therapy early because they do not have enough accurate information about the service, or when they attend therapy it is not what they had expected. According to Gerhand and Blakey (1994) early discontinuation of therapy is due to a “dislike of treatment”. Carpenter et al. (1981) found that patients who had previously attended psychiatry were more likely to attend subsequent psychiatry appointments. This was attributed to previous positive experiences of therapy and knowledge about treatment.

Waiting List Initiatives

The DCP survey (1993) found that various measures had been taken by psychology services in an attempt to decrease waiting lists, including restricting access to the service, a more consultative and training role for clinical psychologists, group work, referring on, brief therapy and opt-in systems. Startup (1988) felt that all except the opt-in system could be seen as avoidance and may result in the client not receiving the optimum care which they deserve. The opt-in system has been one of the more popular initiatives to try to decrease waiting times and its introduction has been widespread. Markham and Beeney (1990) showed a 12% decrease in non-attendance (DNA) rates after the introduction of an opt-in system.

Information leaflets

Patients are often uninformed psychologically and would benefit from information before they attend for therapy. Balfour (1986) and Spector (1988) studied the effects of sending GPs information to give to patients. They both found that this reduced DNA rates and referrals, although have been criticised for confounding results by using an opt-in system at the same time. Green and Giblin (1988) found that DNA rates reduced after the implementation of an opt-in system, but that the provision of information had no such effect. Webster (1992), however, found that 82% of patients who received an information leaflet attended their first appointment compared to 57% who did not receive the leaflet.

Keen, Blakey and Peaker (1996) did not find that sending out an information leaflet with the first appointment influenced DNA or drop out rates. Other studies which found that DNA was affected (e.g. Spector 1988) sent out information at an earlier stage, therefore Keen and colleagues concluded that the information leaflet was only of

benefit if it accompanied the opt-in letter.

Markham and Beeney (1990) reported that almost 90% of their subjects found the information useful and reassuring, although it did not reduce DNA rates and Morrison (1991) reported that “most patients reacted favourably to a pamphlet and their feeling about referral to clinical psychology had changed in the positive direction”.

Possible Service Implications

The recent emphasis on cost-effectiveness in the NHS has resulted in a number of initiatives to try to reduce wasted time including preparing clients for treatment, implementing opt-in systems and providing information about the service as this study has done. Lack of correct information about clinical psychology could be contributing to patient DNA rates. If this is the case an individual who has attended psychology before and has agreed to be re-referred should not terminate therapy early because they know what to expect from the service and have opted in, so must feel that they want the same sort of help again. Providing clients who have not attended psychology before with information could have a similar effect and influence attendance and drop out.

The current study was trying to address a problem apparent in many areas of healthcare today, that of wasted therapy time due to non-attendance and premature discontinuation of therapy. The author was also interested in the opinions of prospective clients about receiving information before they attended psychology and how they rated the leaflet on a number of measures.

Hypotheses

Clients who receive the information leaflet will be:

- 1 - more likely to opt-in to the service and attend the 1st appointment
- 2 - less likely to drop out of therapy early (defined here as 2nd or 3rd appointments)

Clients who read the leaflet will find it:

- 3 - understandable, readable, helpful, informative

METHODS

Participants: All outpatient referrals, excluding neuropsychology, (age 16 and over referred from mental health professionals and GPs) to an Adult Mental Health Clinical Psychology department over a seven week period in 1998 were included (n=69).

Neuropsychology referrals were excluded because it was a separate service with different waiting times. These referrals were compared to 76 referrals from the same period in 1997. In 1998 64% of the referrals were female compared to 54% in 1997. The age range was 17-69 (mean=36) in the 1998 group and 17-68 (mean=34) in the 1997 group. GPs referred 78% of the 1998 group and 70% of the 1997 group. 59% and 50% of the referrals in 1998 and 1997 respectively were for anxiety related problems.

Materials: An information leaflet explaining about the Psychology Service (see appendix 1.2) was used. This leaflet was supplied by another Psychology department and was modified to suit local circumstances. It was presented in A5 booklet form. Using the Flesch Reading Ease Formula (1948) the leaflet was given a readability score of 57.4. This is just below the average writing score which is between 60 and 70 (the

higher the score the more people will understand it). A question sheet (see appendix 1.3) was sent out with the leaflet which asked for ratings and comments on different aspects of the information leaflet.

Procedure: An information leaflet, question sheet and stamped addressed envelope were sent out with the opt-in letter to all the referrals during the 7 weeks. Clients were asked to complete the question sheet after reading the information leaflet and return it to the department in the stamped addressed envelope provided or to bring it to their first appointment. Information about opt-in and attendance rates from 1997 and 1998 was obtained from case notes and the department computer. The data collected included opt-in rates, attendance, cancellation or non-attendance of first, second and third appointments, whether there had been previous psychology contact and whether or not the question sheet was returned.

RESULTS

Insert table 1

There appears to be a slight trend (see table 1) showing that those who received the information leaflet were more likely to opt-in and attend the first appointment, but less likely to terminate therapy early. Chi-square analysis was carried out on the data. The first analysis of whether or not the clients opted in to the service showed that there was no significant difference between the two groups ($\chi^2(1)=0.404$, $p=0.525$). There were no significant differences between the two groups either on first appointment

attendance ($\chi^2(1)=1.193$, $p=0.275$) or early drop out from therapy ($\chi^2(1)=0.210$, $p=0.646$).

It was thought that clients who had attended psychology previously would know about the service and have realistic expectations, therefore would be more likely to opt-in and attend their appointments and less likely to discontinue therapy prematurely than those who had not attended before nor received an information leaflet. Chi-square analysis showed that those who had attended psychology before were not significantly more likely to opt-in to the service ($\chi^2(1)=1.130$, $p=0.288$) or attend their first appointments ($\chi^2(1)=2.462$, $p=0.117$) than those who had not seen a psychologist before, nor were they any less likely to discontinue therapy early ($\chi^2(1)=2.321$, $p=0.128$).

Insert table 2

Chi-square analysis showed that there were no significant differences between the groups in table 2.

Questionnaire results

Twenty-five people (36%) returned the completed questionnaires and significantly more of these ($\chi^2(1)=6.645$, $p=0.01$) clients opted in (100%) and attended their first appointment (92%) ($\chi^2(1)=4.125$, $p=0.04$) than those who did not send the questionnaire back (77% and 70% respectively). Comparison of early discontinuation of therapy between these groups did not quite reach significance at the 0.05 level ($\chi^2(1)=3.445$, $p=0.06$). There were no negative responses to any aspect of the questionnaire and all those who returned the questionnaire reported finding the

information leaflet helpful, informative, understandable and readable. 68% reported it had helped them decide to opt-in and attend their first appointment. A number of respondents reported that the information on “what will happen at my first appointment” was the most useful. Others found the information about confidentiality and what a psychologist is, what they do and how they can help was useful. Only two people felt that they required more information. One wanted to know more details about how a Psychiatrist and Psychologist differ and the other wanted to know how long they would be waiting for an appointment. Only 32% of clients remembered being given any information about psychology by their GP when the referral was suggested.

DISCUSSION

The literature suggests that a lack of information and therapy not matching expectations may contribute to non-attendance and early drop out, so it was thought that sending out an information leaflet to prospective clients could decrease DNA and early discontinuation rates. Implementation of an opt-in system in the department had reduced non-attendance, but there continued to be wasted therapy time when clients DNA or drop out from therapy prematurely.

Results show that sending clients an information leaflet had no significant effect on opt-in rates, first appointment attendance or premature termination of therapy. These results are similar to the findings of Keen et al. (1996) who found that attendance rates and early discontinuation of therapy were not influenced by providing an information leaflet. The present study considered their suggestion that the information leaflet would only be effective if it accompanied the opt-in letter, but this did not result in significant findings. Although the results are not significant it can be seen from table 1 that there is a slight trend favouring the group receiving the information leaflet. A higher

percentage opted in to the service and attended their first appointment and a lower percentage terminated therapy early.

The information leaflet may have influenced opt-in figures in two ways. People who were unsure about psychology may have been encouraged to opt-in to the service when they received more information, but people may also have failed to opt-in if they discovered from the leaflet that what the psychology department was offering was not the kind of help they required or wanted. The information leaflet was expected to increase opting in, but may also have increased opting out of the service and this may have contributed to the results being non-significant.

Carpenter (1991) highlighted that less is known about people who schedule appointments and then DNA. Weighill et al. (1983) found that lower socio-economic status, having children and transport availability influenced attendance. The results from this study suggest that once a person has decided to opt-in factors other than information may influence attendance. After receiving information, providing the client reads it, they should have more realistic expectations about what psychology can offer and so the explanation suggesting that early drop out occurs when therapy does not match expectations should not apply.

The Flesch rating for the leaflet was slightly low. The average writing score is between 60 and 70, whereas the information leaflet was only 57.4 (the higher the score, the more people can understand it). Perhaps the leaflet did not have the desired effect because some clients were unable to read and understand it. If the department decided to provide this service permanently it may be advisable to simplify the content of the leaflet and make it understandable to more of the client group.

Another explanation which has been offered for early termination of therapy is that the client does not like treatment and this is not something that can be influenced by an information leaflet therefore this could account for early discontinuation figures in the study not changing significantly.

Results indicated that patients were not more likely to opt-in or attend appointments if they had previously seen a psychologist and were just as likely to drop out of therapy at an early stage. In the group who received an information leaflet more of the individuals who had seen a psychologist before opted in and attended than those who had not seen a psychologist before, although this was not significant. In a larger scale study it would be interesting to note whether or not the clients had terminated therapy at an early stage when they visited psychology on the previous occasion.

The first set of hypotheses cannot be accepted because the information leaflet did not significantly increase the opt-in rate or first appointment attendance nor did it reduce early termination of therapy. The trend displayed by the data may have been more significant if there had been a larger sample. Future research in this area should consider this and perhaps take the sample over a longer time period.

Only 36% of questionnaires were sent back to the department even although a stamped addressed envelope was enclosed with the letter. A number of patients admitted that they had not read the leaflet, thought they had not received it or had thrown it away. Those who sent back the questionnaire were significantly more likely to opt-in and attend their first appointment and less likely (not significantly) to drop out of therapy than clients who had not returned it. They may have been more likely to opt-in because they had read the leaflet and understood the process of getting an appointment better

than those who did not read the leaflet and perhaps just skimmed over the opt-in letter. The information leaflet may have engaged them into therapy and resulted in them being more likely to attend their appointment. The information leaflet was only expected to have an effect on those who actually read it. We can perhaps assume that many of those who did not return the question sheet did not read the leaflet either, so would not have benefited from the information it contained. Those who returned the question sheets may have been more motivated altogether and may have attended regardless of whether they had received information.

All those who returned the questionnaire said that they found the leaflet understandable, readable, informative and helpful. Clients who did not return the questionnaire, but did attend their first appointment said that they had found the information helpful too. The information which people reported finding most useful was 'What will happen at my first appointment?'.

It was surprising to find that so few of the clients remembered their GPs explaining to them about clinical psychology and this could perhaps be a focus of future research. Was it that they did not remember being told or did the GP not give them information about the psychology service? This may be a better entry point for the information leaflet. The GPs and prospective clients could discuss referral to the psychology service and the information leaflet could be provided at this stage. The client could be asked to read the leaflet and then inform the GP whether they would like to be referred. This could act as another opt-in system and increase the positive effects shown by standard opt-in systems. A much larger sample would be required to draw any strong conclusions from a study of this type, but the author was constrained by the time available.

The information leaflet does, however, appear to have had a positive effect on attendance, opting in and early drop out (although not significant) and clients were very positive about receiving the leaflet and the information it provided. Startup (1988) highlighted that providing information increases consumer satisfaction.

CONCLUSIONS

Although clinical psychology has been a growth area for quite some time many of the general public are unsure of what a clinical psychologist does. To ensure that clinical psychology continues to thrive it must market itself appropriately and using the information leaflet is a cheap and convenient way of doing this. It may also reduce non-attendance slightly, therefore reduce wasted time, increase cost effectiveness and increase therapist morale. Ley and Morris (1984) believed in the patient's right to know and said that patients want information, it does no harm and it is often not provided. The present study showed that participants do not receive adequate information about psychology. They wanted information and when it was provided they found it helpful. This suggests there is good reason to continue providing patients with information about clinical psychology and what it can offer.

Table 1: Percentage of each group who opted in, attended first appointment and discontinued therapy prematurely.

	Received information leaflet (1998 group)	Did not receive information leaflet (1997 group)
Opted in	85%	80%
Attended 1 st appointment	74%	70%
Early discontinuation of therapy	42%	44%

n = 69

76

Table 2: Previous psychology contact and percentage who opted in, attended first appointment and discontinued therapy prematurely

	Received information		Did not receive information	
	Seen psychologist before (27.5%)	Not seen psychologist before (72.5%)	Seen psychologist before (38%)	Not seen psychologist before (62%)
Opted in	95%	82%	86%	86%
Attend 1 st appointment	78%	73%	48%	81%
Early discontinuation	55%	41%	52%	40.5%

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MAJOR PROJECT LITERATURE REVIEW

Neonatal Trauma: Mothers' Psychological Morbidity

Prepared for submission to the *Journal of Reproductive and Infant Psychology*

(See Appendix 2.1 for Notes to Contributors)

Neonatal Trauma: Mothers' Psychological Morbidity

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ABSTRACT

Due to medical advances most premature or low birthweight babies survive, but often require a lengthy hospital stay. Studies show that mothers with a baby in a Neonatal Intensive Care Unit (NICU) experience significant levels of anxiety and depression. Childbirth itself is known to result in emotional disturbances including anxiety and depression in some mothers, but recent research has focused on viewing childbirth from a trauma perspective demonstrating that some mothers experience symptoms similar to post-traumatic stress disorder following delivery. The combination of childbirth, having a premature or low birthweight baby and subsequent neonatal admission has not been addressed within this framework. This gap in the literature must be studied because many of the factors highlighted by previous childbirth research as being important in the development of PTSD are relevant in the field of premature birth and NICU admission.

Key words: Premature, low birthweight, childbirth, NICU, PTSD and postpartum emotional disturbance.

INTRODUCTION

Premature birth and the subsequent hospital admission of infants is known to be very stressful for mothers. Childbirth itself can result in postpartum emotional disturbance, but this can be exacerbated by the additional stresses of premature labour and a child in intensive care. This review will concentrate on the psychological effects of these factors combined and the possibility of addressing these difficulties using theories of psychological trauma.

Preterm birth and subsequent neonatal hospital admission

Preterm birth

When a baby is born prematurely (<37 weeks) or is of low birth weight (<2500g) there is a higher risk of infant death or suffering and physical or mental difficulties compared to that of a full-term infant (Littlewood and McHugh 1997). Recent medical advances, however, mean that the majority of preterm infants born at, or after, 25 weeks gestation survive, but may need prolonged in-patient care.

Onset of a preterm birth is often sudden, with little time for mothers to prepare for the birth or adjust to motherhood. The delivery can result in mothers feeling shocked and anxious due to the fact that their expectations of birth (Taylor and Littlewood 1993) and about the appearance of their child (McHaffie 1990) have been violated. This can be compounded by the subsequent separation from their child, being unable to take their child home and not celebrating the new arrival due to the infant's condition. Younger et al. (1997) reported that mothers of preterm infants showed stress and depression symptoms in the early postpartum period. Mothers of premature babies describe feelings of loss, isolation, loneliness, shock and trauma (Taylor and Littlewood 1993) and more stress (Zarling et al. 1988) than full-term mothers.

Using the Multiple Affect Adjective Checklist-Revised (MAACL-R) Gennaro et al. (1990) reported that parents ($n=27$) of very low birthweight (VLBW, $<1500\text{g}$) preterm infants showed more anxiety and depression symptoms than parents ($n=35$) of low birthweight (LBW, $<2500\text{g}$) preterm infants until 2 months post-birth, but at 3 and 4 months the LBW mothers had higher levels. This demonstrated different patterns of anxiety and depression after birth, but that total anxiety and depression levels over 4 months were not significantly different. Gennaro (1988) using the State Trait Anxiety Inventory and the Depression Adjective Checklist, showed that mothers of preterm babies were significantly more anxious and depressed than a matched sample of mothers of term infants in the first postpartum week. This study, however, had a small sample with 16 mothers of preterm infants being compared to 10 mothers of term infants. Thompson et al. (1993) found that 48% of their sample of mothers of VLBW babies met caseness criteria on the SCL-90-R just after birth and that 33% showed significant distress between 3 and 6 weeks postnatally, however, this study relied on self-report data.

Child's condition

Singer et al. (1999), in their longitudinal prospective follow up study, document that at one month the psychological distress (as measured by the Brief Symptom Inventory and Parenting Stress Index) of mothers of VLBW infants ($n=206$) was greater than that of mothers who had term infants ($n=123$). 13% of VLBW mothers were significantly distressed compared to 1% of term mothers. At one month, mothers of high-risk VLBW babies reported more psychological distress, depression, anxiety and OCD symptoms than low-risk VLBW infants' mothers, who in turn were more distressed than mothers of term babies (high-risk babies had evidence of chronic lung disease, were ventilated for at least 28 days and were born at a VLBW). At 8 months all three groups

were comparable (although the mothers of high-risk VLBW infants showed clinically significant anxiety levels), suggesting that the increase is in the neonatal period.

However, at 2 year follow up the distress levels of mothers of low-risk and term infants did not differ, but the distress of mothers of high-risk infants was higher until 3 years post delivery. 9% of preterm infants' mothers showed severe depressive symptoms and mothers of high-risk infants were more likely to report moderate, but clinically significant depression symptoms and higher distress than low-risk or term mothers. One of this study's strengths is the long follow-up period.

Aradine and Ferketich (1990) described fluctuating emotions according to the infant's progress and other research has shown that a mother's emotional well-being is related to the infant's condition (Affonso et al. 1992) or her perception of it (Shields and Pinelli 1997). Gennaro (1988), however, found no differences in anxiety and depression in mothers according to their infant's level of illness. Padden and Glenn (1997) found, using a semi-structured interview, that the distress of parents whose infants were not critically ill appeared to be similar to the levels shown in other studies which had looked at mothers of infants in intensive care. However, they assessed mothers at a very early stage following delivery (4-9 days) so mothers may not have had sufficient time to adjust to the fact that their child was not critically ill. Results may have been more robust if mothers had been interviewed at a later stage.

In a large study (n=420), Redshaw (1997) found that mothers of smaller, sicker babies in a neonatal intensive care unit (NICU) were more concerned about taking their baby home and less confident about their ability to parent the child. These concerns were significantly increased if the child was born at a younger gestational age or if they required ventilation. O'Brien et al. (1999) found that symptoms decreased when

mothers took their child home, but half of the sample still showed significant symptoms of depression six weeks later.

Neonatal Care Units

Neonatal units can be a very stressful place for mothers (Affonso et al. 1992, Kenner 1990 and Miles et al. 1991), even threatening (Padden and Glenn 1997) where the normal parental role cannot be fulfilled. Being separated from their infant due to hospitalisation and issues pertaining to their baby's health (whether the child will survive and the long-term prognosis) were major stressors for parents (Hughes and McCollum 1994, Redshaw and Harris 1995 and Hughes et al. 1994). Other stressful aspects include the early onset of the birth, the appearance of their child, the hospital equipment, feeling like a failure, not feeling in control of, or lacking confidence in, caring for the baby and feeling guilty because they do not have the perfect baby they had imagined (Brady-Fryer 1994, Bolton et al. 1993, Levy-Shiff and Mogliner 1989 and Sherr 1989).

Bolton et al. (1993) stated that “psychologically difficult adjustments” have to be made after giving birth to an unwell baby who requires intensive care and that parents are often not given enough information about the unit when their child is admitted.

Unmet expectations

Expectant mothers often have assumptions about what happens when a baby is born, for example; they will be born at full-term, they will have a “perfect”, healthy, bouncing child, they will be prepared for the event, they will not be separated from their baby, it will be a positive experience and they will immediately assume the parenting role.

Premature birth and hospital admission of a child often comes as a shock to mothers.

The role they had expected for themselves as a parent is delayed, with the caring role in the unit being very different. In a review paper Affleck and Tennen (1991) suggested that admission to a NICU violated the mother's assumptions about themselves as a mother, the world and their future. Mothers must alter these assumptions following the trauma to prevent longer-term psychological disturbance. This experience fits into the model of post-traumatic reactions proposed by Janoff-Bulman and Frieze (1985). They suggested that people have schemas or assumptions about the world, themselves and the future and if experiences are extremely discrepant from these assumptions people are thrown into conflict and can experience maladaptive coping responses and distress. Mothers' childbirth schemas (expectations of what will happen) may be shattered by preterm birth and subsequent admission to a neonatal unit. This may result in emotional conflict which can be manifested as intrusions and re-experiencing the event as well as denial, avoidance and numbing (see figure 1).

Insert figure 1

Mothers generally are not prepared for hospitalisation or the uncertainty regarding their infant's well-being and it is believed that preparing prospective parents for this possibility would be valuable to decrease the initial shock of admission to such a unit.

Hospital environment

Meyer et al. (1995) reported that levels of psychological distress varied in individuals, but that there were two aspects to the distress, NICU related distress (including the baby's appearance, equipment used, separation) and general distress (sad, irritable, sleep problems) and they looked at the infant and maternal factors which predicted maternal

distress. 18% of the NICU related distress was accounted for by younger gestational age ($r = -.32$) and the need for ventilator support ($r = .34$). They found that 28% of their sample displayed clinically significant distress (three times the normal population) when measured with the SCL-90-R. Once again this study relied on self-report data and did not use a diagnostic tool. Haines et al. (1995) reported that parents were most upset by the noises and sights in the intensive care unit, their child's reaction to treatment and the painful procedures they had to go through. They were significantly more distressed if their child required ventilation. They suggested that parents whose children need intensive care not only required information about the unit, but also about the interventions their child may be subjected to and the expected emotional response of the child. This study included parents of children ranging from 1 week old to 18 years old.

Raeseide (1997) noted that NICUs create barriers (physical and emotional) between parents and their child, but that the stress (assessed by interview) caused by the NICU was not as bad as parents had expected. Shellabarger and Thomson (1993) found that parents with a child in the NICU might feel anxious, guilty, scared or disappointed, all of which may be increased by efforts to adjust to an unfamiliar environment. A common coping method amongst mothers was speaking to their partner (Redshaw and Harris 1995) with many concentrating on the infant's progress to take their mind off things.

Long-term difficulties

The distress caused by the NICU can be chronic (Singer et al. 1999). Wereszczak, Miles and Holditch-Davis (1997) reported that at 3 year follow up many mothers still had clear memories of the stress related to their child's condition and long-term outcome, their child's appearance, the pain and procedures they experienced and their

changed role as parents. Thompson et al. (1993) reported that 41% of mothers still showed psychological distress at 6 months, but other studies (Miles et al. 1991) found that symptoms of stress (measured by the Parental Stressor Scale) decreased over time for NICU parents.

Childbirth and postpartum emotional disturbance

Childbirth results in physical, psychological and social alterations for mothers. The birth can be very intense, painful, women often feel out of control and it can be a time of crisis for first time mothers (Chertok 1969). Most mothers recover quickly, but a small minority suffer significant emotional disturbance which can have a detrimental effect on their lives and the mother-baby interaction.

According to Thune-Larsen and Moller-Pedersen (1988) many factors individually contribute to “postpartum emotional disturbance”, including difficult childbirth, pain during childbirth, loss of awareness, lack of control, anxiety, being unsatisfied with their coping during delivery and negative reactions to the birth. Women who had negative feelings about childbirth reported losing feelings of control during birth and a lack of information (Green 1990).

Emergency operative births are described as being “psychologically difficult” for mothers (Hannah et al. 1992) and Ballinger (1982) found significantly increased anxiety and depression in the first few days after caesarian section when compared to vaginal delivery (although this study did not control for previous births).

The most commonly researched emotional difficulties in the postpartum period are postnatal depression and anxiety, but more recently childbirth has been viewed from a

trauma perspective and the post-traumatic symptoms which some mothers experience have been considered. Having a premature birth and the subsequent admission of the baby to a NICU can be considered traumatic and is usually outwith any expectations prospective mothers have, but research has not addressed this using theories of psychological trauma.

Emotional disturbance following childbirth

Postnatal depression

There are many concerns about disturbances in the mother-child relationship that can occur when postnatal depression develops and this has resulted in much research. Recent estimates (Righetti-Veltema et al. 1998 and Bergant et al. 1999) report that between 10 and 20% of mothers suffer from postnatal depression. Righetti-Veltema (1998) assessed an unselected sample of women (n=570) during pregnancy and reported that negative life events, a negative birth experience, early separation from the child, multiparity and depression before birth were influential in the development of depression. Factors thought to increase vulnerability to postnatal depression include obstetric complications (Bergant et al. 1999), lack of social support, poor control over the environment, subjective experiences of labour and dysfunctional parenting (Green 1990 and Bolton et al. 1993).

In 1999 O'Brien et al. (1999) reported that half of their sample (n=45) of mothers of premature infants displayed depressive symptoms above the cut-off point for clinical depression on the CES-D (Center for Epidemiological Studies-Depression Scale). Lower levels of partner support and the impact the infant has on the mother's life influenced the development of depressive symptoms. Symptoms were higher when the infant was hospitalised compared to 1-2 weeks and 6-7 weeks post discharge, although

at six weeks 21 of the mothers still showed significant depressive symptoms. Cox et al. (1984) found that more than half of their sample of mothers of term babies had not recovered after one year. Research shows that this is an important area to consider in the field of premature birth and subsequent NICU admission.

Post-traumatic stress following childbirth

Looking at childbirth from the perspective of trauma, according to Lindstrom (1996), is important because often women are labeled as having postnatal depression rather than having post-traumatic stress, therefore are managed inappropriately.

Expectations of childbirth

Our cultural stereotype that becoming a mother is an entirely positive experience, according to Oakley (1980) contributes to postpartum distress and feelings of failure by influencing mothers' perceptions of their experience. Instead of being predictable and positive, childbirth may be frightening, mothers may feel out of control and fear for their own or their infant's safety (Crompton 1996).

Prospective mothers are said to possess a "childbirth schema" (Pierce 1984). If these expectations are not met they may feel helpless and despairing and must attempt to revise the schema to integrate the actual birth experience. Janoff-Bulman and Frieze (1985) suggested that if core schemas and assumptions about a situation are violated individuals may be vulnerable to developing post-traumatic stress symptoms. Laizner and Jeans (1990) stated that if childbirth was worse than the mother expected, had included obstetric treatments or the pregnancy had been difficult they were more likely to suffer from postpartum emotional disturbance. Other studies report that if mothers perceive the birth as having been a traumatic shock other psychological difficulties

(Konrad 1987, Crowe and von Baeyer 1989) may result.

Previous literature

PTSD has been reported after stressful medical and surgical procedures (Shalev et al. 1973), in mothers of burn victims (Rizzone et al. 1994), mothers of paediatric cancer survivors (Manne et al. 1998), following obstetric and gynaecological procedures (Menage 1993) and following miscarriage (Frost and Condon 1996). The doctor's attitude, the degree to which the mothers' views are heeded, level of information given and extent of control were important factors developing these post-traumatic symptoms (Menage 1993). Bowles et al. (2000) reported that 10% of their sample met criteria for ASD and 1% for PTSD following spontaneous abortion. It is known that childbirth can trigger similar symptoms, but research in this field is limited.

However, as far back as 1978, Bydlowski and Raoul-Duval's case series described "la nevrose traumatique post-obstetricale" which highlighted that after prolonged or difficult labour, forceps delivery, infant mortality or injury the mother was more susceptible to postpartum psychological difficulties showing a prevalence of 0.2% (10/4400). Reynolds (1997) called this type of reaction after childbirth a "traumatic birth experience" because she found that presentation was often short of a full diagnosis of PTSD.

Studies have found (Wijma et al. 1997, Ballard et al. 1995 and Allen 1998) that some women report clinically significant post-traumatic stress symptoms following childbirth. Wijma and colleagues (Wijma et al. 1997) guided by DSM-IV criteria found that 1.7% (28/1640) of their unselected population met criteria for post-traumatic stress disorder following childbirth and that this type of presentation was significantly correlated with

previous psychological or psychiatric treatment, nulliparity and viewing a previous delivery negatively.

In a qualitative analysis (Allen 1998), 10 months post delivery (using the revised Impact of Events Scale) 6 out of the sample of 20 women scored above the cut-off level indicating “caseness” and 2 scored in the borderline range. Previous negative birth experiences, pain, powerlessness, lack of information, lack of staff sympathy and beliefs about the baby’s well-being were found to be related to the mother losing feelings of control and developing post-traumatic stress symptoms. Although the sample in this study was small, Allen took into consideration whether or not the mother considered the birth as traumatic and she selected the sample from 145 mothers. Unfortunately she did not compare this sample with mothers who did not consider the birth as traumatic, nor did she use a diagnostic tool.

Lyons (1998) reported that symptoms of PTSD in first time mothers 1 month after birth significantly correlated with feeling out of control during delivery, a difficult pregnancy or induced labour. Ballard et al. (1995) found that 1% of their sample (n=163) had PTSD symptoms within 48 hours of childbirth and in each case this was associated with delivery (long, complicated labour) and depressive illness. Symptoms were very similar to DSM-III R criteria and they speculated that the prevalence was probably higher than 1%, but that most cases were probably not being recognised. Czarnocka and Slade (2000) found that 3% of their sample of 264 mothers had significant PTSD symptoms, however they did not take into consideration the perception of the event as traumatic. In Josephs’ (1996) report of 2 cases she states that the trauma of childbirth can reactivate psychological symptoms caused by previous trauma.

Long-term difficulties

O'Brien et al. (1999) commented that little progress had been made in the identification of women who are at risk of developing postpartum psychological disturbances, but as the above literature shows, much has been done to determine which factors contribute to such problems. Padawer et al. (1988) thought that denial in the early postnatal stages could result in mothers appearing to be adjusting successfully, but that birth trauma may not appear for weeks or months.

The symptoms can be chronic. Niven (1986), at follow up 3-4 years after delivery showed that most could remember all aspects of the birth and some mild post-traumatic stress symptoms relating to the birth were still apparent. One case study (Fones 1986) described a woman who displayed PTSD nine years after childbirth.

Postnatal emotional problems can affect the mother's ability to breast-feed, bond with the child, may result in avoidance of future pregnancy or resuming sexual activity, lower the mother's self worth (Reynolds 1997), and have a deleterious impact on the whole family (Weaver 1997).

Conclusions and future research

Emotional disturbance following childbirth is a well researched area of interest, but as yet the combination of a preterm birth and the baby's subsequent admission to neonatal care has not been investigated within a trauma perspective.

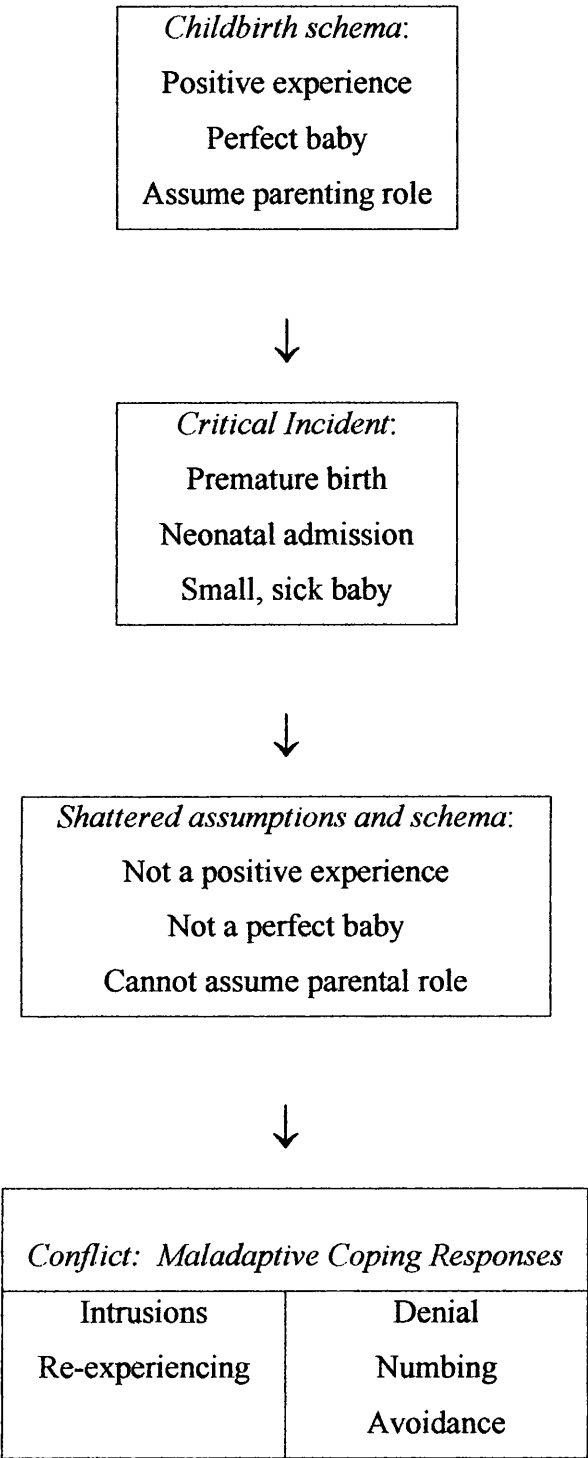
Childbirth literature has emphasised that unmet expectations, traumatic birth, obstetric complications, operative births and lack of control are all factors contributing to the development of post-traumatic symptoms, many of which are relevant when an infant is

born early and admitted to the NICU.

Previous childbirth and PTSD literature has often been anecdotal, case studies or had small sample sizes and often symptoms have not met DSM-IV criteria for PTSD (although are very similar). Very few of the studies took into account the perception of the event as traumatic (which is a key factor in the development of PTSD) nor did they use a diagnostic tool to identify PTSD symptoms. Some studies have indicated that distress is short lived, perhaps indicating Acute Stress Disorder. Future research may want to concentrate on these factors to determine the exact effects of this type of trauma on women.

Singer et al. (1999) stated that 'at risk' mothers should be identified in the neonatal period by using screening techniques, which may prevent the mother developing chronic symptoms. Mothers experiencing PTSD symptoms require to be identified early and receive the necessary intervention (Weaver 1997). These symptoms can be prolonged and have great effect on the lives of the whole family therefore the psychological needs of these mothers must be identified by future research to ensure they are receiving appropriate support during this distressing time.

Figure 1: Janoff-Bulman and Frieze’s shattered assumptions model of PTSD applied to premature birth and neonatal admission



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MAJOR RESEARCH PROJECT PROPOSAL

Traumatic Neonatal Events: Mothers' Psychological Morbidity

DEIRDRE FORREST

Word count: 2007

SUMMARY

Mothers of neonates requiring in-patient care have many difficulties to contend with. They may have experienced an unexpected traumatic birth where they were uncertain of whether they or the child would survive. The baby is often premature and this can add to the concerns of the mother. Zarling et al. (1988) found that mothers of preterm infants experienced more stress than mothers of full-term babies.

Neonatal In-Patient Care Units can be very stressful for mothers. They may feel like an intruder in this unfamiliar environment. Mothers are unable to carry out the normal parenting role and on some occasions will not have been able to hold their child. Neonatal units can create barriers, both physical and emotional, between the mother and the baby.

The aim of this study is to determine the psychological profiles of mothers whose infants require special care or intensive care and to view their reactions from the perspective of theories of psychological trauma. Compared to intensive care babies special care babies tend to be less unwell, in hospital for a shorter period of time and their long-term health prognosis is usually good. These mothers may also be compared to those whose infants did not require in-patient care. Mothers who were aware that their child may need in-patient care during pregnancy will be compared to those who only found out during or after the birth.

The participants will be recruited from the Queen Mother's Maternity Hospital, Glasgow and will be mothers with infants in the special care and intensive care units. A variety of measures will be used including modules of the Structured Clinical Interview

for DSM-IV (SCID), a semi-structured interview, the Hospital Anxiety and Depression Scale (HADS) and the PENN inventory.

- It is thought that:
- 1) mothers with an infant in a neonatal in-patient care unit will show emotional distress
 - 2) mothers with infants in intensive care will display more psychological symptoms than mothers whose infants are in the special care unit or not in hospital at all.
 - 3) mothers who were prepared for their infant requiring in-patient care will show fewer difficulties than those who only found out during or after the birth.
 - 4) symptoms will change over time

(Word Count 364)

INTRODUCTION

Following uncomplicated childbirth mothers may experience a number of psychological symptoms, for example anxiety, depression and, in some cases, post-traumatic stress symptoms. Having an infant in a neonatal in-patient unit is a source of anxiety in itself, but the mother has often had to contend with a traumatic birth, a preterm birth and low birthweight baby (all of which have been shown to be sufficient for the development of psychological difficulties). Often mothers will not have envisaged any of the aforementioned difficulties and may be unprepared both physically and mentally for the new arrival. Hans (1986) suggested that if mothers' birth expectations were not met they may require assistance in understanding the experience.

Postnatal depression

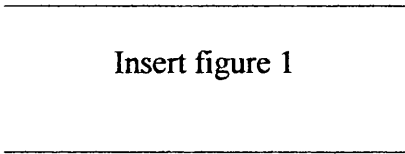
There has been much research in this field and concern about disturbances that can occur in the mother-child relationship. There are many factors thought to increase vulnerability to postnatal depression including stressful life events during pregnancy and the puerperium (Paykel et al. 1980), obstetric complications (Kumar and Robson 1984), lack of social support (Cowan and Cowan 1988) and poor control over the environment (Hayworth et al. 1980). Mothers with infants requiring in-patient care may have experienced a number of the above factors.

Post-traumatic stress

Shalev et al. (1993) reported post-traumatic stress disorder (PTSD) in patients following stressful medical and surgical procedures and it is thought that childbirth could trigger similar symptoms. Mothers may have felt their own or their baby's life was in danger during the birth and could have experienced feelings of helplessness or horror (which

are fundamental DSM-IV requirements for the development of PTSD). How the mother perceives the birth is a key factor in the development of PTSD symptoms. Others may perceive the birth as being uncomplicated, but if the mother has experienced it as traumatic she is at risk of developing post-trauma symptoms.

During pregnancy mothers have expectations of childbirth and becoming a parent and these may not have been met resulting in the birth being perceived negatively (which Lyons (1998) found to be significantly related to PTSD occurrence in first time mothers). Pierce (1994) felt that if a mother’s experience was far removed from her “childbirth schema” the birth may be perceived as negative, resulting in helplessness or PTSD symptoms. This theory is compatible with that of Janoff-Bulman and Frieze (1985), (see figure 1). They postulated that when core assumptions about a situation were not met or were violated individuals may experience conflict and employ maladaptive coping strategies.



Manne et al. (1998) reported that a child’s cancer treatment could trigger the development of PTSD in the mother. This highlights that the invasive procedures which an infant may have to endure in hospital could also be a sufficient trigger for PTSD or Acute Stress Disorder (ASD).

Preterm and low birth weight (LBW) infants

Taylor and Littlewood (1993) found that mothers of premature babies described a feeling of loss, isolation, loneliness, shock and trauma whereas mothers of full-term babies recalled a positive experience. Gennaro et al.(1990) reported that parents of very low birthweight (<1500g) preterm infants showed more anxiety and depression symptoms than parents of low birthweight (<2500g) preterm infants. Younger et al. (1997) and Zarling et al. (1988) reported that mothers of preterm infants had significant levels of stress and depression. McHaffie (1990) found that having a preterm or LBW infant may infringe on the expectations of oneself as a mother and of the baby. This can result in mothers viewing themselves as a failure and contribute to the development of psychological difficulties.

Neonatal In-Patient Care

Mothers of neonates requiring in-patient care have often experienced a traumatic birth (where they were uncertain of whether the child or they themselves would survive) and the baby is often preterm or of low birth weight. In addition they have the stresses of a neonatal in-patient care unit to contend with. Mothers may feel like an intruder in the unfamiliar hospital environment and this may add to their feelings of distress. They are often unable to carry out a normal caring role and may not have been able to hold their child. Hughes and McCollum (1994) reported that physical separation and worries related to the infant's health were the most severe stressors for parents.

Raeside (1997) noted that in-patient units create barriers (physical and emotional) between parents and their child. Shellabarger and Thomson (1993) found that parents with a child in the Neonatal Intensive Care Units (NICU) might experience guilt,

anxiety, fear and disappointment, heightened by trying to adapt to the unfamiliar environment. Some mothers will only have to endure these units for a few days whereas others will be uncertain of how long their child will require in-patient care and this may continue for months.

Affleck and Tennan (1991) reported that mothers whose infants required hospitalisation have their expectation of a positive pregnancy outcome shattered. Mothers who know during pregnancy that their infant will require in-patient care may show fewer psychological difficulties due to the fact that they may feel more prepared for this outcome.

Infants in special care units are less unwell than infants in intensive care. Their stay in hospital is usually fairly short and the outcome is clearer with long-term health likely to be good. Mothers with infants in intensive care may be uncertain how long their child will remain in hospital, the long-term outcome or whether they will actually survive.

The aim of this study is to describe the psychological profiles of mothers whose infants (born at less than 32 weeks gestational age) require neonatal in-patient care and determine the prevalence of post-trauma symptoms. Factors associated with the mothers' childbirth schema will be considered, for example the mother's preparedness for their child's hospital admission and whether or not their expectations have been met with regards to the pregnancy, labour, birth and postnatal period. The change in symptoms over time will also be monitored.

GAPS IN THE LITERATURE

There has been much research into postnatal psychological symptoms, the effects of having a preterm infant and having an infant in a neonatal unit, but this study considers this experience from the perspective of theories of psychological trauma and is largely exploratory as this particular area has not been fully researched in the past.

AIMS AND HYPOTHESES

The aim of the study is to describe the features and degree of distress experienced by mothers with babies in a neonatal care unit. This study is largely exploratory, so the hypotheses are tentative, but it is thought that having a newborn admitted to the unit is likely to be a traumatic stressor which could precipitate an acute stress reaction or post-traumatic stress symptoms.

AIMS:

1. To describe the psychological profiles of mothers whose infants require in-patient neonatal care.
2. To compare the psychological profiles of mothers whose infants are in the intensive care unit with those who have infants in the special care baby unit.
3. To compare the psychological profiles of mothers who were aware during pregnancy that there may be complications with the birth and that their child may require hospitalisation to mothers who discovered this during or after the birth. It is thought that with this prior knowledge their expectations of childbirth and parenthood may not be totally violated.

4. To assess the change in symptoms over time.

HYPOTHESES:

1. Mothers whose infants require in-patient care will display some psychological difficulties.
2. Mothers whose infants require intensive care will display more psychological symptoms than mothers whose infants require only special care.
3. Mothers who were aware during pregnancy that there may be complications with the birth and that their child may require hospitalisation will display fewer psychological symptoms than mothers who discovered this during or after the birth.
4. Symptoms will decrease over time.

PLAN OF INVESTIGATION

Application to the Yorkhill Ethics Committee has been made. The mothers will be contacted within the first month after delivery and interviewed whilst the child is still in hospital using a number of measures. A repeat measure will be administered 3 months after the first interview. The mothers will be given a letter containing information about who they can contact should they feel that they need advice or assistance (see appendix 3.1). There will also be a protocol that will be put into place if a participant becomes notably distressed (see appendix 3.2) and the researcher feels that they require formal psychological input.

PARTICIPANTS

Study Group

Mothers of infants born at less than 32 weeks gestational age (at the Queen Mother's Maternity Hospital) who require intensive or special care will be identified for potential inclusion in the proposed study. They will be offered the opportunity to participate in this study and will be given information about what this would entail (see appendix 3.3). If they decide to participate in the study they will be required to complete a consent form (see appendix 3.4) which will be put in the hospital case notes and their GP will be notified by letter (see appendix 3.5) about their inclusion in the study. It is hoped that a sample of approximately 60 participants will be obtained.

Comparison Group

Time constraint permitting this group may be introduced for comparison purposes. Mothers of infants who did not require in-patient care will be matched to the study group according to age and number previous births. A sample of 30 participants would be aimed for.

MEASURES

A semi-structured interview (see appendix 3.6), devised for use in this study, will be administered to all the participants at the initial interview to determine demographic details, information about the pregnancy, birth and previous births. Modules of the Structured Clinical Interview for DSM-IV (SCID) (First et al. 1997) will be also be given to determine the psychological symptoms that the participants may be experiencing. The Penn Inventory (Hammarberg 1992) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) will be used at initial interview

and at 3 month follow-up to measure change in distress levels over time.

DESIGN AND PROCEDURES

This study will be both a between and within groups design. Data collection in the form of interviews will take place between June 1999 and February 2000 and follow-up data collection will continue until May 2000. The mothers will be contacted between 1 and 4 weeks after delivery and asked if they would be willing to participate in the research. Once written consent is obtained the SCID, the semi-structured interview, the PENN inventory and the HADS will be administered. Three months after this initial assessment the PENN inventory and HADS will be sent to participants to complete and return.

DATA ANALYSIS

Each participant will be given a reference number and information obtained at interview will be anonymous. The analysis of the data will be both qualitative and quantitative. The different groups will be compared using inferential and descriptive statistics with SPSS 9.0 for Windows package. As this is a largely exploratory study there is no directly comparable study, so a power calculation was made using Aradine and Ferketich's 1990 study ("The psychological impact of premature birth on mothers and fathers") which matched the proposed study to the greatest degree. The calculation for a power of 0.8 at 0.05 significance indicated that the present study would need 10 subjects on the anxiety measure and 28 on the depression measure which suggests that 30 subjects would be sufficient.

PRACTICAL APPLICATIONS

This study could help to identify the mothers most at risk of developing psychological difficulties. Many of these mothers may be suffering from a range of psychological symptoms and without appropriate screening will not be offered the help and guidance they need. These mothers may require a more comprehensive service pre and postnatally. Information could be given as early as the ante-natal classes to highlight possible psychological difficulties which could occur after the birth and the help that could be requested should they require it. Appropriate screening measures could be used by staff to identify the mothers who might benefit from psychological intervention.

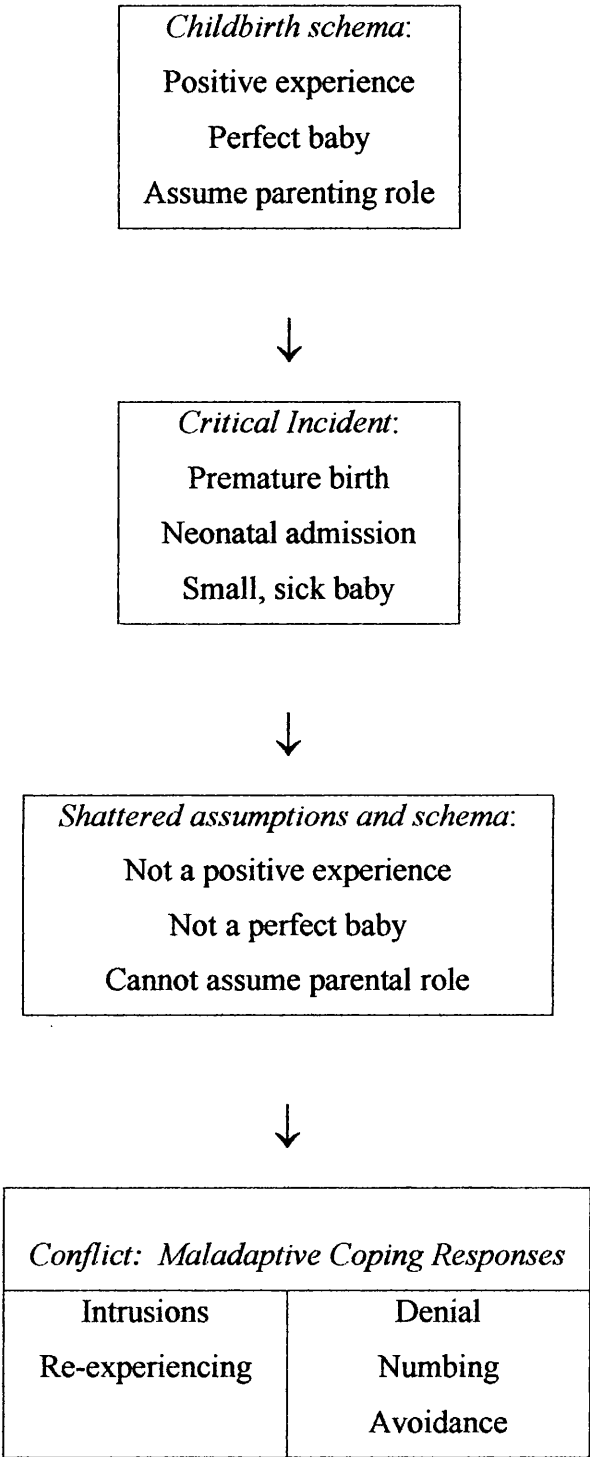
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June 1999 - February 2000

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Journal of Reproductive and Infant Psychology

Figure 1: Janoff-Bulman and Frieze’s shattered assumptions model of PTSD applied to premature birth and neonatal admission



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AMENDMENTS TO MAJOR RESEARCH PROPOSAL

1. Due to time constraints a comparison group was not introduced. The data collected in this study will, however, be compared to normative data from previous research.
2. Mothers whose infants were born at less than or equal to 36 weeks gestational age were recruited rather than 32 weeks as specified in the proposal. This would have limited the numbers too much. Less than 37 weeks gestation is considered premature, so this change did not interfere with the aims of the study.
3. Three mothers were interviewed within the first week after delivery. These were all mothers whose infants were admitted to the special care baby unit for a short period. To enable them to be interviewed on the ward this was completed within the first week before discharge. Four mothers were interviewed more than a month after delivery partly because of the difficulties of recruiting mothers in the first few weeks. In the early stages after delivery they often wanted to get into a routine and were making physical and emotional adjustments to their situation, so delayed taking part in the study. The fact that the interviews were conducted at different times postnatally (ranging between one and eleven weeks) will be taken into account in the analysis.
4. Although it was hoped that sixty mothers would be recruited, only fifty-four were interviewed due to the time constraint and lack of mothers who fitted the research criteria. However, these numbers are adequate and meet the power calculation, which suggested that a sample of thirty would be sufficient.

5. Due to the pattern of admissions to the unit it was not possible to recruit two equal groups. There were significantly more infants who were admitted to the intensive care unit in the first instance. This was also taken into account in the analysis.
6. Following completion of an extensive literature search it became apparent that taking into account the mother's perception of whether she experienced the event as traumatic would be a key factor. It was hypothesised that mothers who reported that the experience was traumatic would have higher distress levels. It also became clear that aim three should be extended to include mothers' expectations of pregnancy and childbirth and whether or not they had been met. If expectations had not been met it was thought that mothers would experience elevated distress levels.

MAJOR RESEARCH PROJECT PAPER

Neonatal trauma: Mothers' psychological morbidity

Prepared for submission to the *Journal of Reproductive and Infant Psychology*
(see Appendix 4.1 for Notes to Contributors)

Neonatal trauma: Mothers' psychological morbidity

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ABSTRACT

This exploratory study aimed to build a psychological profile of mothers who had premature infants admitted to a neonatal unit. This experience was considered within the theoretical perspective of psychological trauma. A significant minority of mothers who had an infant in a neonatal unit following premature birth displayed psychological distress. Using the Hospital Anxiety and Depression Scale 26% and 13% had significant anxiety and depression symptoms respectively, 15% of mothers were above the cut-off on the Penn Inventory and 21% of mothers met criteria for a DSM-IV diagnosis. Factors which were associated with increased levels of distress included having a child in intensive care, a child on ventilation, a longer hospital stay and having a smaller, younger infant. Premature childbirth and subsequent neonatal admission was viewed as traumatic by some mothers and they were more likely to develop significant anxiety, depression and post-traumatic stress symptoms. Experiences far removed from mothers' expectations in terms of parenting role and the child's appearance were also associated with increased distress levels. These results suggest that this experience, especially if perceived as traumatic by the mother, is a possible trigger for distress, including post-traumatic stress symptoms. This highlights that increased professional awareness of the possibility of mothers developing these symptoms and provision of appropriate services for mothers is essential.

Word Count: 214

INTRODUCTION

Premature birth (when a baby is born at less than thirty seven weeks gestation) often has a sudden, unexpected onset and mothers may not have time to prepare psychologically or receive information about what is going to happen. From the moment the child is born there may be uncertainty regarding their wellbeing and survival. Mothers may be separated from their child almost immediately which they report, according to Redshaw and Harris (1995), is one of the worst aspects of this experience.

Advances in neonatal medicine mean that most babies born after twenty-five weeks gestation survive, but may require a long hospital stay and suffer long-term health complications. Mothers of preterm infants have been shown to suffer from higher levels of stress and depression (Younger et al. 1997) than mothers of term infants and Redshaw (1997) reported that mothers of smaller, sicker babies became more distressed.

Neonatal intensive care units (NICUs) are said to create physical and emotional barriers between the mother and child and mothers may feel that they do not have a role in the unit. They may feel guilty because they do not have the “perfect” baby they had hoped for and there may be no celebrations for the new arrival. Continued uncertainty about the infant’s long-term health and survival increase the stress for mothers and significant psychological adjustments need to be made. The treatment and equipment used in neonatal units can be distressing for mothers (Affleck and Tennan 1991) and their emotional distress levels are reportedly higher if their child is ventilated (Haines et al. 1997). The emotional difficulties experienced by mothers, in many cases, do not appear to be transient. Wereszczak et al. (1997) found that some mothers still had clear memories of their distressing experience three years after the event. However, some studies have reported that symptoms tend to decrease over time (Miles et al. 1991).

Expectant mothers have assumptions about childbirth and their future as a parent. Premature birth and neonatal admission often violate these expectations (O'Brien et al 1999); mothers are not able to carry out a normal parenting role; they may lose their identity as a mother now and in the future; it is not the bouncing baby they had hoped for; nor has it been a positive experience (McHaffie 1990, Taylor and Littlewood 1993). Janoff-Bulman and Frieze (1985) emphasised the importance of basic assumptions about situations and when they are shattered maladaptive coping responses may result. This model can be applied to the experience of premature birth and infant hospital admission (see figure 1).

Insert figure 1

It is well accepted and recognised that normal childbirth can precipitate anxiety and depression (Aradine and Ferketich 1990, Righetti-Veltima et al. 1999). There has, however, been a recent increase in interest in post-traumatic stress disorder (PTSD) following childbirth. Events that involve actual or threatened death to a person or others or pose a threat to their own or others' physical integrity are considered sufficient to trigger PTSD symptoms. Weaver (1997) raised a key point that mothers' perceptions of the event are important in the development of distress. Others may not consider the event as traumatic, but if a mother has experienced it this way she may be at risk of developing PTSD or acute stress disorder (ASD).

Research has shown that PTSD can occur after childbirth (with a typical prevalence when using DSM III-R criteria of 1-3%). Reynolds (1997) called this type of reaction a "traumatic birth experience" because she found that symptoms often fell short of a

diagnosis of PTSD. Many of the studies researching this field have been criticised for small numbers, anecdotal reports, failing to use a diagnostic interview schedule, not taking into account the individual's perception of the event and reported rates no greater than in the general population (see Forrest 2000 for a review of the literature).

PTSD has also been reported after medical and surgical events (Shalev et al. 1973), following obstetric and gynaecological procedures (Menage (1993) and by mothers of paediatric cancer survivors and burns victims (Manne et al. 1998, Rizzone et al. 1994). The serious nature of events leading up to premature birth and the infant's admission to hospital suggest that this experience may increase the likelihood of mothers regarding the experience as traumatic and being at risk of developing PTSD or Acute Stress Disorder (ASD). Often the distinction between ASD and PTSD is not made, however Bowles et al. (2000) acknowledged that the short-term reaction of ASD was prevalent in women who had suffered spontaneous abortion (10%) as was PTSD (1%).

Due to the potentially chronic and serious nature of PTSD, mothers suffering from these symptoms need to be identified. Currently many may be mislabeled due to professionals not considering or recognising post-trauma symptomatology. Progress to identify mothers of premature infants who may be at risk of developing psychological difficulties has been slow (O'Brien et al. 1999) and to date there have been no studies addressing trauma symptoms.

The main aims of this study were to assess the psychological profiles of mothers who had given birth prematurely and had their infant admitted to a neonatal unit and to determine the prevalence of post-trauma symptoms in this potentially high-risk population.

METHODS

DESIGN

Once ethical approval was given by Yorkhill Ethics Committee (see appendix 4.8) a between and within-subjects design with repeated measures was used to assess the emotional experiences of mothers whose infants were admitted to an intensive or special care unit. A power calculation made using Aradine and Ferketich's (1990) paper (which matched the present study to the greatest degree) indicated that the present study required thirty participants to reach a power of 0.8 at 0.05 significance.

PARTICIPANTS

Fifty-four mothers of premature infants, who had all been admitted to the Paediatric department of a Glasgow hospital, gave written informed consent to participate in this study. It was proposed that mothers of all consecutive admissions to the units meeting the study criteria would be approached to participate. However, this was not possible because some infants were only admitted for a matter of hours or days or the baby did not survive. Thirty-nine percent of mothers who were given information about the study declined to participate giving reasons such as, they were not interested in taking part, they felt unable to talk about the experience or they did not have time. Savitz et al. (1999) found similar problems with patient refusal. During the data collection period 628 babies were admitted to the Paediatric department. 369 of these were born at normal birthweight and were full-term, 28 babies were born at a weight considered light for their gestational age and 231 were premature babies.

PROCEDURE

Data were collected over a nine-month period. Interviews took place between 3 and 77 days after delivery (mean=16.74, SD=12.31). One mother was excluded from the

analysis because she was interviewed seven months after delivery. If mothers gave consent to participate in the study they were interviewed at the hospital. The interview consisted of a structured clinical interview, a semi-structured interview and two self-report questionnaires and lasted between thirty and sixty minutes. The interview was confidential from hospital staff, but consent forms were put in the case notes and GPs were informed of their patient's participation in the study. Three months after the initial interview participants were sent the two self-report questionnaires to complete and return. Three mothers who participated in the initial stage of the study were not contacted because their babies had died since the initial interview and it was felt that it was inappropriate to contact them.

Sections of the Structured Clinical Interview for DSM-IV (SCID) (First et al. 1997) were administered. Screening questions were asked, then the appropriate sections were completed. It has been shown to have excellent reliability and validity (Williams et al. 1992).

In the past there have been attempts to measure schemas. Tools which have been devised include Janoff-Bulman's world assumption scale (1989) and Young's schema questionnaire (Young & Brown 1994) and these have been used to measure basic assumptions and schema and shifts in general schema. It was thought these tools were not pertinent to this population and their schematic shifts, however it was beyond the scope of this study to develop a specific measure to assess childbirth schemas or expectations. It was also decided that due to practical considerations (e.g. the mothers' distress) that using a further questionnaire measure would not be appropriate, therefore a semi-structured interview aimed to measure factors relating to participants' childbirth schema in an exploratory fashion was devised. It was designed to elicit information

about the mother, any previous pregnancies and births, her recent pregnancy and birth, her emotional reactions to these, expectancies regarding the pregnancy and birth and schema related information. It was thought that violations of mothers birth expectations may result in schematic shifts therefore it was important to assess expectations too. The semi-structured interview was not administered in a rigid manner and many questions were answered by mothers during the course of describing their experience. The interview schedule was merely used as a guide for the interviewer and questions were posed using lay terms. Inter-rater reliability (for the semi-structured interview) was calculated using Cohen's kappa coefficient (1960) which discounts expected chance agreements and takes into account the observed proportion of agreement. The kappa coefficient was 0.94 which Cohen and Holliday (1982) describe as "very high".

The Penn Inventory (Hammarberg 1992) was used to assess PTSD symptoms at the time of the initial interview and at three month follow-up. This twenty-six item scale has been shown to have good validity and is easy to administer (Hammarberg 1992). A cut-off score of thirty-five or above was used to indicate significant PTSD symptomatology. This questionnaire has high internal consistency (0.94), test retest reliability and validity in relation to diagnosing PTSD and has been found to have a sensitivity of 98% and specificity of 94% (Hammarberg 1992). It was chosen because the questions apply to all trauma types and could be used with the study's population. Previous studies have commonly used the Impacts of Events Scale (Horowitz et. al 1979) which assesses the extent of avoidance, numbing and intrusive symptoms rather than the full range of PTSD symptoms and focusses on re-experiencing of past events and recollections of the trauma. It was thought that this was not appropriate for the purposes of this study because most participants were still faced with potentially traumatic events every day and were unable to avoid reminders of their distressing

experience. Due to these factors, as well as the Penn's established cut-off point and the good psychometric properties of both the Penn and SCID it was thought they would give a more accurate measure of trauma symptomatology in this population.

Anxiety and depression were measured at initial interview and three month follow-up using the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983). This is a fourteen item self-report scale (with seven anxiety items and seven depression items) which was devised for a medical outpatient population. It is quick and easy to administer (Herrmann 1997) and is not reliant on somatic symptoms therefore it is "considered unbiased by coexisting general medical conditions" (Snaith 1987). The authors suggest that a cut-off eleven or above indicates significant anxiety or depression. It has an internal consistency of 0.80 (anxiety) and 0.81 (depression), the test retest reliability of the anxiety and depression scales are 0.84 and 0.85 respectively (Herrmann 1997) and Spinhoven et al. (1997) reported that using a cut-off of eleven indicated a sensitivity of 89% and specificity of 66%.

RESULTS

The SPSS for Windows statistical package, version 9.0 was used to analyse data. Independent t-tests were used for interval data, Wilcoxon matched pairs test for repeated measures, chi-square tests for categorical data and Mann Whitney-U tests to compare groups of differing sizes and those which did not meet the assumptions necessary to perform parametric analysis. Pearson and Spearman's rho correlations were used to determine relationships between data. The Kolmogorov-Smirnov test was used to test the normality of the population distributions.

DEMOGRAPHICS

The mothers’ ages ranged from 18 to 39, with 79% of the sample between the age of 20 and 35. Only 8% were younger than 20 and 13% older than 35. These figures are similar to a national audit of all births in Scotland (McIlwaine et al. 1994) which found that 7% of mothers were younger than 20, 83% were between 20 and 34 and 10% were 35 or older. Thirty-six (68%) mothers reported that they had experienced life events in the previous twelve months and fourteen (25%) of the mothers had seen a psychologist, psychiatrist or a counsellor in the past (see appendix 4.2 for further demographic details).

Fifty-two percent of mothers had other children, (between 1 and 7), with a median number of zero children. The majority of participants were married or co-habiting and had been working before the birth (see table 1).

Insert table 1

Gestational age correlated positively ($r=0.81$, $p<0.001$, 1-tailed Pearson correlation) with birth weight. Birth weight and gestational age showed significant negative correlations ($r_s=-0.720$, $r_s=-0.791$, $p<0.001$, 1-tailed Spearman’s rho) with total days spent in hospital. The total number of days in hospital also correlated positively ($r_s=0.704$, $p<0.001$) with the number of days a child was ventilated for. Thirty-four percent of the sample had infants born between 34 and 36 weeks gestation, forty percent between 30 and 33 weeks and twenty-six percent at less than 30 weeks. Fifteen percent of infants were born at normal birth weight (more than 2500 grams), forty-five percent at low birth weight ($<2500g$), twenty-six percent at very low birth weight ($<1500g$) and

thirteen percent at an extremely low birth weight (<1000g) (see table 2 for infant characteristics). A National Audit conducted in Scotland in 1994 found that 6.5% of infants were born prematurely, just over five percent were born between 32 and 36 weeks gestation, 0.8% were born between 28 and 31 weeks and less than 0.5% at less than 27 weeks.

Insert table 2

Most of the babies (81%) in the present study were admitted to intensive care in the first instance and of these, 57% were ventilated (mean= 19 days, range 1-150, SD=39.4). Only 22.6% of infants had a normal delivery. Caesarian section accounted for 73.6% of deliveries (23% of these were under general anaesthetic) and 3.8% percent were either a breech or instrumental delivery. McIlwaine et al. (1994) reported that only 16% of the total births in Scotland were by caesarian. 15% of mothers in the current study had twins.

SYMPTOM PROFILE OF MOTHERS

On the HAD Scale a cut-off of score of 11 or above was used to indicate clinically significant anxiety and depression symptoms and on the PENN inventory a score of 35 or above was used. Seven (13%) of the sample reported significant symptoms on the HADS depression scale (range 0-16, mean=5.34, SD=4.00) and fourteen (26%) on the anxiety scale (range 0-16, mean = 7.72, SD = 4.36). Eight (15%) mothers reported significant symptoms on the Penn inventory (range 7-51, mean=22.06, SD=10.11). Five mothers had clinically significant symptoms on all three measures, two mothers on two of the measures and ten had significant symptoms on one questionnaire measure.

Birth weight and gestational age were negatively associated with anxiety and depression (see table 3) and birthweight was also negatively associated with scores on the Penn inventory (see appendix 4.3 for questionnaire scores related to gestation and birthweight). A longer stay in the neonatal unit was associated with increased mothers' anxiety levels. Number of children, age, occupational status, social support, previous birth distress and timing of the interview did not have any association with distress scores (HADS or Penn inventory). Recent life events and previous contact with psychology or psychiatry did not have a significant association with distress levels either.

Insert table 3 + 3A

Mothers whose infants were ventilated had elevated anxiety scores ($t(51)=3.77$, $p<0.001$) and higher depression ($U(51)=195.5$, $p=0.006$) scores on the HADS and PTSD symptoms ($U(51)=216.00$, $p=0.02$) using the Penn inventory. Ventilation is generally an indicator that the child is sicker than non-ventilated infants and requires help breathing. Increased time on a ventilator was correlated with higher anxiety, depression and post-traumatic stress symptoms in mothers (see table 3). They were also more likely meet criteria for a DSM-IV diagnosis ($\chi^2(1)=4.115$, $p=0.04$, 1-tailed) or present with partial PTSD (met criteria for a DSM-IV diagnosis in all but one of the subscales) ($\chi^2(1)=5.04$, $p=0.05$, 1-tailed).

It is not clear which individual factors resulted in elevated distress levels (on the HADS and Penn inventory). Using stepwise regression 20% of the variance in HADS anxiety scores was explained by infant ventilation, but no more than 14% of the variance of

HADS depression or Penn inventory scores was explained by any one factor. Although experiencing the birth as traumatic and having a younger, lighter baby did not explain significant amounts of the variance they were all correlated with distress levels (See table 3 and 6 for correlations between factors).

Using the SCID 68% of the sample reported significant DSM-IV symptoms. This included the thirty-three (62%) mothers who reported partial PTSD (meeting criteria in all but one of the DSM-IV PTSD diagnostic categories) or full PTSD. Three of the sample (6%) reported significant depressive symptomatology on the SCID.

Insert table 4

As can be seen from table 4, twenty-one percent of the sample reached a DSM-IV diagnosis, with two percent fulfilling criteria for PTSD, fifteen percent for ASD and four percent for major depression (see appendix 4.4 for details about the profile of mothers who met DSM-IV diagnosis criteria). These diagnoses were mutually exclusive and none of the sample showed co-morbidity.

The PTSD and ASD symptoms which were reported most often by mothers were feeling unreal (74%), feeling as if they were in a daze (62%), more than one arousal symptom (42%) and one or more re-experiencing symptoms (51%). Significant avoidance symptoms were only reported by 23% of the sample.

PERCEPTION OF THE EVENT AS TRAUMATIC

Twenty-six (49%) mothers reported at initial interview that they perceived the experience as traumatic with more mothers in the ITU unit appraising the event as traumatic ($\chi^2(1)=7.523$, Fishers exact $p=0.01$, one-tailed). Seven (27%) of these mothers were above the Penn inventory cut-off and four (15%) met DSM-IV PTSD or ASD criteria. They were more likely to report higher distress levels on the HADS anxiety ($U(51)=212.00$, $p=0.013$) and depression ($U(51)=239.00$, $p=0.045$) scales and the Penn inventory ($U(51)=231.5$, $p=0.03$). Mothers who the researcher rated as having had a traumatic experience had higher symptoms of anxiety ($U(51)=206.00$, $p=0.01$), depression ($U(51)=213.5$, $p=0.014$) and Penn inventory scores ($U(51)=210.00$, $p=0.012$). (See appendix 4.5 for words mothers used to describe their feelings at different stages of their experience).

COMPARING INTENSIVE CARE AND SPECIAL CARE BABY UNITS

Only ten of the sample were not admitted to intensive care (ITU) during their stay, therefore the majority of the sample (81%) spent a period in ITU. ITU infants were in hospital for significantly longer (Mean=46.88 days, SD=35.36, Range=0-154) than those in the SCBU (Mean=14.2, SD=9.28, Range=0-42), ($U(51)=47.5$, $p<0.001$). The weight ($U(51)=71.5$, $p<0.001$) and gestational age ($U(51)=75.5$, $p<0.001$) of the infants in ITU (Mean=1576g and 31 weeks) were significantly less than those in the SCBU (Mean=2269g and 34 weeks), (see appendix 4.6 for between unit differences in weight and age and information regarding ventilation and birth factors).

HADS anxiety and depression scores were significantly less ($U(51)=113.5$, $p=0.02$, $U(51)=97.5$, $p=0.01$) for mothers whose infant had only been in special care, but there were no significant differences on the Penn inventory scores (see figure 2).

Insert figure 2

The method of delivery was not significantly different between units and neither was the interviewer's perception of the birth or the mothers' feelings of preparedness. Analysis showed that mothers in the intensive care unit were significantly more likely have DSM-IV symptoms ($\chi^2(1)=5.461$, Fisher's exact $p=0.03$), but not a DSM-IV diagnosis.

PRIOR KNOWLEDGE OF POSSIBLE COMPLICATIONS

Sixty-four percent of the sample were aware that there may be complications before the birth. This did not appear to have a significant effect on anxiety, depression, PTSD symptomatology or DSM-IV diagnosis. Other factors of preparedness were considered, for example previous birth distress, parity, whether the mother reported being surprised and whether expectations had been met. Previous birth distress (which 18% reported) increased feelings of preparedness, however this did not influence self-report distress. Previous birth complications (32%), being primiparous (41.5%) or surprised by what had happened (85%) did not significantly influence distress levels. Those reporting that the birth experience had been negative were more likely to have clinically significant anxiety ($t(51)=-1.996$, $p=0.05$), but not depression or trauma symptoms (a negative birth experience is not the same as a traumatic experience. More mothers reported a negative experience. See questions 39 and 57 in appendix 3.6).

Mothers who reported that their pregnancy, labour and birth had been worse than expected (as opposed to the same or better) were no more likely to report greater

distress levels on the HADS or Penn inventory, but mothers who, at the time of interview, felt worse than they had expected to reported significantly higher anxiety levels ($t(51)=-2.139$, $p=0.04$), but not higher depression or Penn inventory scores (see table 5).

Insert table 5

Other factors relating to childbirth schema, for example, the child's appearance and size, the parenting role, separation from the child and seeing the child upset were significantly associated with self-report distress scores (see table 6 and appendix 4.7).

Insert table 6

FOLLOW-UP DETAILS

Thirty (59%) of the postal follow-up questionnaires were returned. Mothers who did not respond to the questionnaire were more likely to have had an infant who was in hospital for longer ($U(51)=236.5$, $p=0.05$) and was ventilated for a longer period ($U(51)=225.00$, $p=0.024$). There was no difference between responders and non responders on initial questionnaire measures (see table 7) or other factors associated with the experience.

Insert table 7

Although the distress levels recorded at initial interview for non-responders were slightly higher than those who did respond no significant differences were found. A Wilcoxon Matched Pairs test showed that the responders showed no significant changes in symptomatology over the 3 month period (see table 8 for questionnaire scores).

Insert table 8

When each reply was analysed individually it was found that fifteen (50%) mothers had distress scores which decreased on all three questionnaire measures and ten (33%) had scores which had increased. Five (17%) mothers increased on some measures, decreased on others or they remained the same.

Chi-square analysis showed no significant differences between neonatal unit, delivery type, gestational age, weight or total days in hospital and follow-up distress scores. Neither were there any differences in follow-up distress scores in those who reached a DSM-IV diagnosis or had ventilated infants. Self-report data at initial interview was significantly correlated with follow-up levels (see table 9).

Insert table 9

DISCUSSION

Using diagnostic criteria anxiety and depression levels in the female population have been reported by Gater et al (1998) as being 9.2% and 12.5% respectively and Breslau

et al (1998) reported that after exposure to a traumatic event 9.2% of people develop PTSD.

Previous childbirth literature (the limitations of which are highlighted by Forrest (2000)) has often found slightly higher levels of distress. Following childbirth Stuart et al (1998) found that 8.7% of mothers suffer from anxiety and 23.3% suffer from depression. Using the Edinburgh Postnatal Distress Scale Righetti-Veltema et al. (1998) found that 10.2% of their sample had clinically significant depressive symptoms. Other studies report that depression occurs in 10-15% of new mothers (Kendell 1985, O'Hara (1987), Hannah et al. (1992)). Thomson et al. (1993) using the SCL-90-R reported significant anxiety levels in 33% of their group of term mothers (3-6 months postnatally), however Singer et al. (1999) found that only 7% of term mothers had significant anxiety symptoms compared to 23% of mothers whose infants were at higher risk. Levels of PTSD following childbirth range between 1-3 percent (Wijma et al. (1997), Ballard et al. (1995), Czarnocka and Slade (2000)) when diagnosis was based on DSM-IV criteria.

Due to the fact that previous studies have used various different measures and have rarely used a diagnostic tool it was difficult to compare the current results to previous findings. Using the HADS the present study found that 27% and 13% of mothers reported significant levels of anxiety and depression and significant trauma symptoms measured by the Penn inventory were reported by 15% of the sample. The levels of anxiety, depression and PTSD reported in this study are higher than that estimates of the levels in the general and childbirth populations. Using the more robust measure of the SCID (which allows some comparison to both general population and PTSD following childbirth literature due to the common use of diagnostic criteria) a more conservative

estimate of depression (4%) was found, however PTSD or ASD diagnoses were found in 17% of the current study's sample. Using a diagnostic interview tool (ASDI, which is based on DSM-IV criteria (APA 1994)) Harvey and Bryant (1998) found that after car accidents 13% of their sample developed ASD (which is similar to levels found in the present study) and 78% of these went on to develop PTSD. 27% of mothers in this study who perceived the event as traumatic were above Penn inventory cut-off levels (15% reached a DSM-IV diagnosis) which is not dissimilar to rates reported by Ursano et al. (1999) who found that 34% of individuals develop PTSD after a car accident.

Information processing theories have been used to explain the development of PTSD (e.g. Horowitz 1976, Resick & Schnicke 1992). These theories emphasise the role of schemas and the fact that information can only be processed in the light of existing schemas. If information does not match that in existing schemas, conflict results and individuals are unable to comprehend, encode or store events and strong emotions can remain unprocessed. When applied to childbirth these theories would expect that events which were far removed from a mother's schema may cause conflict and maladaptive coping. The trauma symptomatology experienced by these mothers have been described within the framework of Janoff-Bulman and Frieze's shattered assumption theory. They suggested that after a traumatic event peoples' beliefs about themselves and the world are violated and their perceptions now mark danger, insecurity and threat. This loss of sense of safety may result in protective behaviours (e.g. avoidance and numbing) which enable "victims" to deal with their reactions (high arousal and intrusions). Mothers in this study often reported that their expectations of childbirth and motherhood had been shattered and as a result some experienced significant post-traumatic stress symptoms. It was thought experiences further removed from schema expectations (for example a very small child, intensive care, child on ventilation or

violation of parenting role) would result in more distress. This was the case with mothers of smaller, younger babies (who are usually in intensive care and have a longer stay in hospital) being most distressed. Having their child ventilated resulted in more anxiety, depression and trauma symptomatology. Ideally, mothers schemas and pre-birth expectations could have been measured during pregnancy and then again at stages following birth to assess whether expectations had been violated and if this resulted in a schematic shift. Unfortunately, this was well beyond the scope of this study.

Mothers who perceived the experience as traumatic had greater anxiety, depression and trauma symptoms and were more likely to have a DSM-IV diagnosis. Perception of the event is a key element in developing post-traumatic symptoms and although some mothers could be judged to have had a traumatic experience they did not perceive it as such and may not have developed distress symptoms. Of those who perceived the event as traumatic ninety-six percent were intensive care mothers.

For many of the mothers their pregnancy, labour, birth and the postnatal period did not meet their expectations. Those who were feeling worse than they had expected to in the postnatal period had higher anxiety scores, but feeling this way at other stages of the experience did not influence distress levels. These results may have been contaminated by retrospective analysis by mothers and it would have been more helpful to assess these feelings at each different stage.

It was hypothesised that mothers who knew of possible complications prior to the birth would feel more prepared and their expectations would not be shattered to the same extent as mothers who did not know until during or after the birth. This was not the case as no differences were found. Mothers may have experienced high levels of

distress throughout the pregnancy which continued after birth or it may have been because the complications were more serious and therefore more discrepant from their schema, thus resulting in greater distress. This merits further investigation.

Mothers experienced increased anxiety and trauma levels when they were unable to fulfill their expected role, for example were separated from or could not care for their child. Those who found the appearance or size of their child upsetting also reported higher levels of anxiety and depression. Significant psychological adjustments would have been required when the outcome was not of a “perfect baby” and mothers were not able to assume the parenting role.

Although there was not a significant difference between reported symptomatology at the initial and follow-up interviews some mothers increased on all measures (34%) and some decreased (49%) on all measures. Many mothers continued to suffer from high levels of distress up to five months after birth. Follow-up levels of distress were highly correlated to those reported in the initial interview which is an important factor for staff to consider when trying to identify mothers who may not adjust well in the long-term.

59% of the follow-up questionnaires were returned and those who did not respond to the postal follow-up were more likely to have had an infant on ventilation and in hospital for a longer period. It is not clear how symptoms changed when mothers were discharged from hospital and more detailed investigations at this stage would have been interesting.

Factors that have been found to be associated with increased distress levels in other studies including life events, social support, psychiatric history and parousness did not appear to be associated with distress scores in this study.

LIMITATIONS

A number of mothers who refused to participate in the study reported that they did not feel able to talk about their experience, also some were never contacted because they did not visit the unit regularly. Avoidance is a primary symptom of trauma reactions and it may have been the case that many of the more distressed mothers were not contacted and that the prevalence of trauma symptoms was actually higher. The level of reported avoidance symptoms was relatively low and this may have been because mothers who visited the unit were unable to avoid being faced with reminders or talking about the event.

Mothers were aware that they would have to talk about their distressing experiences at the interview, yet many still agreed to participate in the study. Some mothers expressed that they thought it may be helpful for them to talk about the experience which suggests that the more distressed mothers were willing to take part. However, it seems likely that many mothers were missed due to their avoidance symptomatology which highlights the importance of contacting mothers who are trying to avoid reminders of the event and may actually be experiencing trauma symptoms.

There were unequal groups when comparing intensive and special care mothers and this was taken into account in the analysis. Often infants were intensive care only for a few days so perhaps a comparison of mothers of these infants together with special care infants versus long stay intensive care infants would have been interesting.

Follow-up was 3 months after the initial interview, but initial interviews took place at different times after birth. This was not associated with distress levels, but it may have been helpful to interview mothers at the same stage postnatally. Some mothers in the study had only been home for a few days at follow-up and three still had infants in hospital. Previous research has indicated that trauma symptoms are not transient so longer follow-up may have been more informative to assess chronicity of symptoms.

This is clearly a population who could benefit from psychological interventions.

Screening for distress at an early stage would be beneficial because many of these mothers remain distressed after three-months and there was shown to be a correlation between initial and follow-up levels.

The events leading to a premature birth and subsequent neonatal admission are sufficient to trigger a post-traumatic reaction, however perception of the event is a key factor. This study found a higher prevalence of post-traumatic symptoms than in the normal birth population, but similar to the literature which looks at other traumatic events, for example, car accidents. It cannot be ignored that up to one in five mothers may be suffering from significant psychological difficulties.

FUTURE DIRECTION

Few professionals receive sufficient training in the psychological difficulties which can arise after birth and many are not aware of the possibility of mothers developing trauma symptoms. Staff must be able to identify mothers who are at risk of developing or are suffering from psychological distress. Preventative measures which have been suggested by previous research include increased staff training, providing mothers with

information regarding possible trauma symptomatology and helping agencies at antenatal classes and screening mothers at an early stage for trauma symptoms.

This is an area of great need which requires development in the areas of prevention, identification and intervention. Physicians and nursing staff alike currently may not be considering ASD or PTSD as a possibility, but as this study shows it is a reality for many mothers.

Figure 1: Janoff-Bulman and Frieze’s shattered assumptions model of PTSD applied to premature birth and neonatal admission

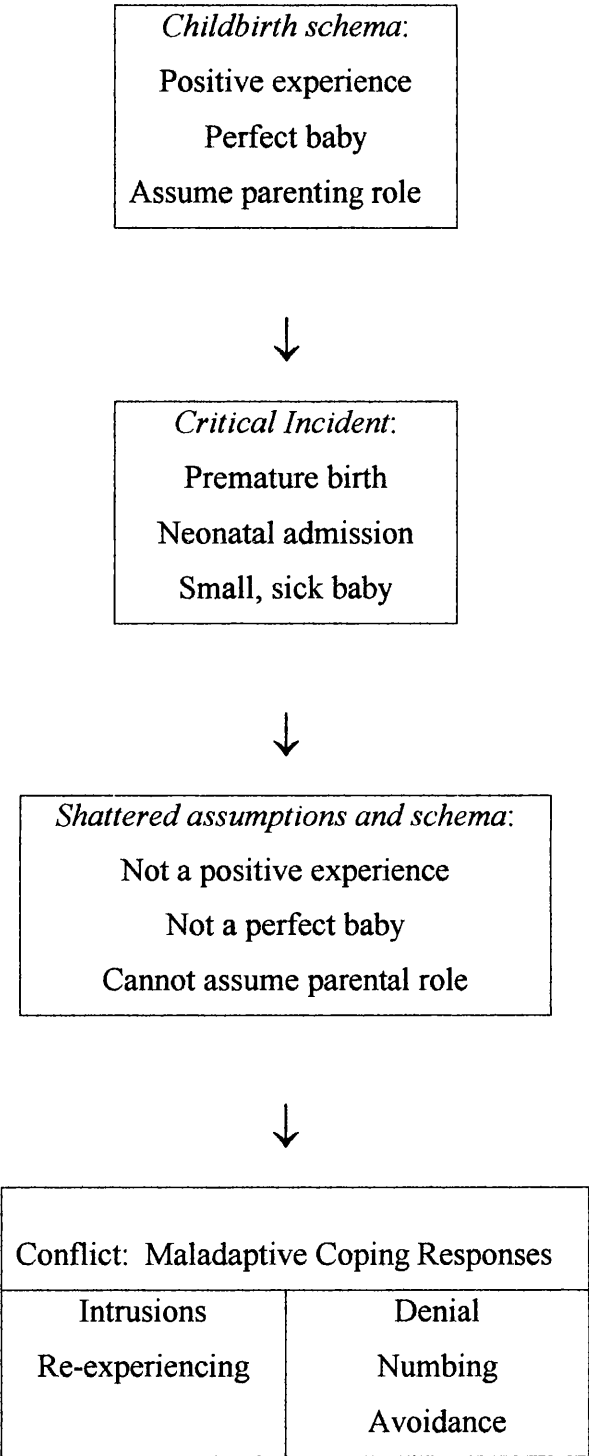


Figure 2: Neonatal unit and distress scores

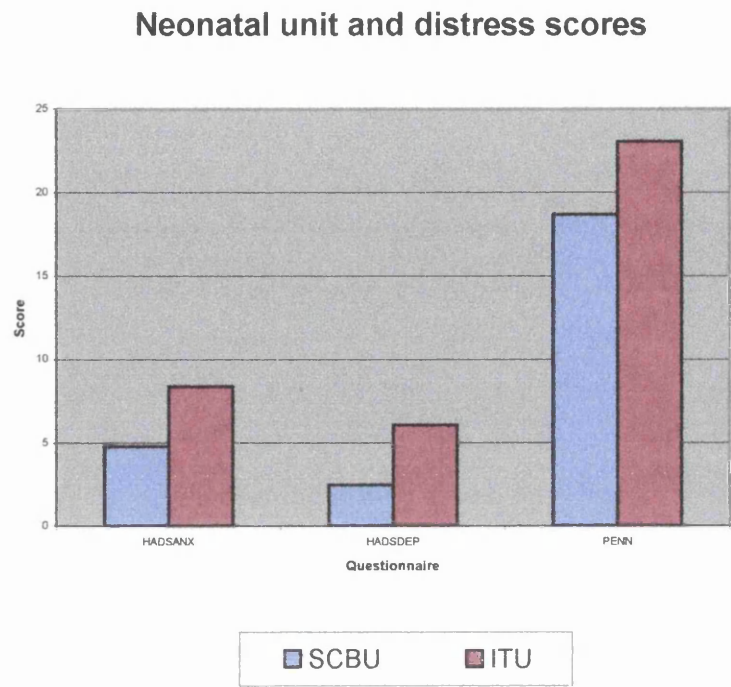


Table 1: Maternal characteristics

	Yes	No
Married / Cohabiting	89%	11%
Employed	81%	19%
Primiparous	41.5%	58.5%

Table 2: Infant characteristics

	Mean	SD	Range
Gestational age	31.6 weeks	2.82 weeks	25-36 weeks
Birth weight	1.71kg	0.62kg	0.78 – 2.96kg
Days in unit	40.72 days	34.50 days	5-160 days
Days ventilated	19.4 days	39.38 days	1-150 days

Table 3: Spearman’s correlation with distress scores and infant characteristics

	Anxiety	Depression	Penn scores
LBW	rs = -0.368**	rs = -0.291*	rs = -0.248*
Gestational age	rs=-0.319*	rs =-0.288*	rs = NS
Days in hospital	rs =0.319**	rs = 0.228 (NS)	rs = 0.200 (NS)
Age when interviewed	rs = 0.228 (NS)	rs = 0.025 (NS)	rs = 0.109 (NS)
Ventilation days	rs = 0.345**	rs = 0.346**	rs = 0.272*
Number of children	rs = -0.223 (NS)	rs = 0.101 (NS)	rs = -0.024 (NS)

*= significance at 0.05 level

**= significance at 0.01 level

NS = not significant

Table 3A: Independent t-tests and Mann-Whitney analysis on demographic factors and mothers’ self-report distress levels

	Anxiety	Depression	PENN
Recent life events	0.310 (NS)	0.455 (MW) (NS)	0.063 (MW) (NS)
Social support	0.374 (NS)	0.981 (MW) (NS)	0.671 (MW) (NS)
Age	0.308 (NS)	0.073 (MW) (NS)	0.537 (MW) (NS)
Occupational status	0.428 (NS)	0.568 (MW) (NS)	0.861 (MW) (NS)
Previous birth distress	0.570 (NS)	0.645 (MW) (NS)	0.956 (MW) (NS)
Previous contact with psychology or psychiatry	0.482 (NS)	0.400 (MW) (NS)	0.241 (MW) (NS)

NS = not significant

MW = Mann-Whitney analysis

Table 4: DSM-IV symptoms and diagnoses measured using the SCID

	Symptoms	Diagnosis
Depression	6%	4%
PTSD	38%	2%
Acute Stress Disorder	41.5%	15%
Subclinical levels	38%	79%

Table 5: Mean questionnaire scores and perception of the birth experience

	Anxiety	Depression	PTSD
Traumatic	9.3	6.6	25.3
Not traumatic	6.2	4.1	18.9
Negative	9.5	6.7	24.8
Positive/neutral	6.4	4.3	20.1

Table 6: Independent t-test and Mann Whitney analysis on factors relating to the neonatal unit and mothers distress levels

	HADS anxiety	HADS depression	PENN
Unexpected appearance / size of baby	0.005***	0.03* (MW)	NS (MW)
Not being able to care for child	0.01**	NS (MW)	0.01** (MW)
Being separated from child	0.01**	NS (MW)	0.03* (MW)
Ventilation	0.00***	0.004** (MW)	0.05* (MW)
Baby crying	0.00***	0.04* (MW)	NS (MW)
Equipment used	NS	NS	NS
Treatment used	NS	NS	NS

- * significant at 0.05 level
- ** significant at 0.01 level
- *** significant at 0.001 level

MW = Mann Whitney analysis

**Table 7: Mean initial interview questionnaire scores of responders and non-
responders**

	Anxiety	Depression	PTSD
Responders	7.2	4.8	21.6
Non-responders	8.4	6.1	22.7

Table 8: Mean questionnaire scores of responders at initial interview and follow-up

	Anxiety	Depression	PTSD
Initial	7.7	5.3	22.1
Follow-up	6.9	4.3	23.3

Table 9: Spearman’s correlations between initial and follow-up distress scores.

	Follow-up HADS anxiety	Follow-up HADS depression	Follow-up Penn Inventory
HADS Anxiety	rs=0.628**	rs=0.363*	rs=0.392*
HADS Depression	rs=0.495**	rs=0.491**	rs=0.483**
Penn Inventory	rs=0.431**	NS	rs=0.528**

** Significance at 0.01 level

* Significance at 0.05 level

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APPENDIX 1.1

Health Bulletin

Notes for Contributors

Papers, articles and other communications should be sent to the Editor, Health Bulletin, Scottish Office Department of Health, Room 143, St Andrew’s House, Edinburgh EH1 3DE. They must be submitted exclusively for Health Bulletin. Acceptance is on the understanding that editorial revision may be necessary. All papers are reviewed by the Editor and by peer review, referees being drawn from a panel of appropriate professionals in the NHS in Scotland. No correspondence can be entered into about articles found unsuitable and returned to authors.

Material submitted for publication must be typewritten on one side of the paper only, in double spacing and with adequate margins and each page should be numbered. The top typed copy should be submitted, with four other copies. All papers should be prefaced by a structured Abstract, of about 250 words in length. It should normally contain 6 clearly headed sections entitled Objective, Design, Setting, Subjects, Results and Conclusion. The name, appointment and place of work of the authors should be supplied on a separate title page. The same page should include the full postal address of one author, to whom correspondence and reprints will be directed. There should be adequate references to any relevant previous work on the subject; these references should appear at the end of the material on a separate page or pages, using the Vancouver style, which in the case of papers in journals includes:

Surname and initials of author(s)

Title of paper

Full name of Journal

Year published

Volume number

Opening and closing page numbers

Reference to books should similarly include author's name and initials, full title, edition (if necessary), place of publication, publisher's name, year, and if required volume number, chapter number or page number.

Short communications. The Bulletin now publishes short communications (not exceeding three pages in length) as a separate section, and we aim to offer speedier publication for these. Material intended for this section should be submitted in the above form, and the covering letter should state the intention.

Copyright. The material in Health Bulletin is in copyright. Items may be freely reproduced in professional journals, provided that suitable acknowledgement is made and that reproduction is not associated with any form of advertising material. In other cases, permission to reproduce extracts should be sought through the Editor from HMSO Publishing Division (Copyright Section), which controls the copyright.

Proofs

Contributors will receive one set of proofs. It should be read carefully for printer's errors, and any tables, figures and legends should be checked. Alterations should be kept to a minimum, and the proofs should be promptly returned.

Reprints

One hundred reprints will be supplied free of charge. A limited extra number (for

which a charge will be made) may be ordered from the Editor when the proofs are returned.

APPENDIX 1.2

(This information was presented in double-sided A5 leaflet form)

INFORMATION FOR USERS OF THE PSYCHOLOGY SERVICES

What is a Psychologist?

A Psychologist is trained to understand how people think, feel and behave. This training includes an Undergraduate Degree in Psychology, a Higher Degree, and supervised practical experience. A fully qualified Clinical Psychologist is one who has successfully completed the training recognised by the British Psychological Society, and who abides by a code of conduct which ensures a high professional standard. A Counselling Psychologist works in a slightly different way, but has the same rigorous training and professional requirements.

Psychologists use therapy based on specialised knowledge of psychological functioning. If their Higher Degree is a Doctorate they will be called “Doctor”, but they are not medical doctors or Psychiatrists and do not prescribe medication.

What does a Psychologist do?

Clinical and Counselling Psychologists work in the Health Services and deal with a wide range of problems. These are often related to anxiety, fears, depression, physical illness or problems coping with various circumstances or events.

Psychologists may help people recognise and avoid situations which can lead to psychological harm. They will use therapy to treat problems which already exist and are causing difficulty, and may support people recovering from their problems and

help them to adjust.

How can a Psychologist help?

When a person comes to see a Psychologist they are often referred to as a patient or client. In general, Psychologists help clients to help themselves. Clients should be willing to be active in order for the treatment to be successful. A partnership is established between the Client and the Psychologist where both identify the problem and agree on the type of treatment and how fast it should go.

What happens once I have been referred?

Once you have been referred to the Psychology Service, you will receive a letter from us saying that you have been placed on the waiting list. You will be asked in this letter to confirm that you will attend an appointment once one is offered. When an appointment becomes available you will be contacted again by letter giving you an appointment date and time. If you leave a phone number, and a cancellation occurs, then the secretary may contact you to offer you an appointment at short notice.

In order to keep the waiting list to a minimum it is very important that you inform us as soon as possible if you are unable to attend. This appointment can then be used to see another Client, and you can also be given a more convenient date. If the Psychology Service does not hear from you when you have missed an appointment, then no further appointments will be offered. If you then decide that you want another appointment you will have to return to the person who referred you and ask to be re-referred. If circumstances change or problems become more urgent while you are waiting for an appointment, either contact your doctor or the person who

referred you.

What will happen at my first appointment?

The first appointment can last up to an hour. This time is used to discuss your problems and how they are affecting your life. You may be asked about the past as well as the present, and you may fill out some questionnaires. You will be given the opportunity to ask questions which are important to you. This may be difficult for you at first, but Psychologists are used to talking about all sorts of problems and take them all seriously.

If you decide you wish to continue attending and the psychologist believes that this will help, a course of treatment will be decided and agreed upon together. Further appointments will usually continue with the same psychologist. Sometimes you may be asked to attend with your partner, and sometimes there are groups (e.g. stress management groups) which might also be suitable for you.

Is everything confidential?

Everyone working in the NHS is under a legal duty to keep your records confidential. So that Health services can work well, different agencies often need to work together and share information about a patient or client, now and in the future. For example, your GP will be kept informed of your progress. Anyone receiving information about you must respect the need for confidentiality. If there is some information you do not want to be passed on you should tell your Psychologist at the first appointment. In certain circumstances information about a patient may be passed on:

- if it is required by law or court order

- for detection or prevention of serious crime
- to protect the public or yourself from serious harm.

If I have a query?

If you are unhappy with any aspect of your treatment, we would like to know so that we can put things right if we can. First of all, try to discuss this with your Psychologist. If you feel unable to do this then you can contact the Head of the Psychology Service, the Clinical Director, or the Chief Executive.

Mr David Martinage	Dr Roger Sykes
Consultant Clinical Psychologist	Clinical Director
Head of Service	Ravenscraig Hospital
Department of Clinical Psychology	Greenock
Ravenscraig Hospital	
Greenock	

Chief Executive

Renfrewshire Healthcare NHS Trust

Dykebar Hospital

Paisley

Acknowledgements to the CCPS, Ayrshire who supplied the original information leaflet which has been altered to suit local circumstances.

APPENDIX 1.3

We are conducting a survey into the usefulness of the enclosed information leaflet.

It would be much appreciated if you could answer the following questions.

1. Have you seen a Clinical or Counselling Psychologist before? YES/NO

2. Did you read the enclosed leaflet? YES/NO

If yes go on to question 3. If no, thank you for answering the questionnaire.

3. Did you understand the leaflet? YES/NO

If no - what did you not understand? _____

4. Did you find the leaflet helpful? YES/NO

If yes - what part was most useful? _____

5. Was the leaflet readable? YES/NO

If no - what was hard to read? _____

6. Did you find the leaflet informative? YES/NO

If yes - what was most informative? _____

7. Did you feel that there was anything missing from the leaflet/anything else you needed to know? YES/NO

If yes - what? _____

8. Was there information on the leaflet which surprised you? YES/NO

If yes - what? _____

9. Did your GP give you any information about what clinical psychology would offer?

YES/NO

If yes - what? _____ Was it accurate? _____

10. Did reading the leaflet help you decide to confirm that you wanted an appointment?

YES/NO

11. Did reading the leaflet help you decide to attend your appointment? YES/NO

If you require more room to answer these questions please write over the page putting the question number beside your comments.

Please return this sheet in the enclosed stamped addressed envelope or bring it to your first appointment.

APPENDIX 2.1

Journal of Reproductive and Infant Psychology

Notes for Contributors

Journal of Reproductive and Infant Psychology welcomes reports of original research and creative or critical review articles which make an original contribution. Articles should not currently be submitted for publication elsewhere.

Topics of interest to the journal include medical, behavioural, cognitive, affective, dynamic, psychological, societal and social aspects of: fertility and infertility; menstruation and menopause; pregnancy and childbirth; antenatal preparation; motherhood and fatherhood; neonatology and early infancy; infant feeding; early parent-child relationships; postnatal psychological disturbance and psychiatric illness; obstetric and gynaecology including preparation for medical procedures; psychology of women.

The journal also publishes brief reports, comment articles and special issues dealing with innovative and controversial topics. A review section reports on new books and training material.

Studies of both human and animal subjects are welcome.

Papers should be sent in the first instance to any one of the Editors:

Suzanne Zeedyk, Department of Psychology, The University of Dundee, Dundee, DD1 4HN, UK;

Ken Gannon, St Bartholomew's & The Royal London School of Medicine and Dentistry, School of Occupational Therapy, Turner Street, London E1 2AD, UK;

John Worobey, Department of Nutritional Sciences, Rutgers University, Turner Street, London E1 2AD, UK;

Mechthild Papousek, Institute for Social Pediatrics and Youth Medicine, University of Munich, Heiglhofstr.63, D-81377 Munich, Germany

Contributions should be as concise as possible and should not normally exceed 5000 words or the equivalent lineage including tables and figures. The title should be brief but precise. Each paper should be accompanied by an abstract of not more than 200 words.

Papers should be typed on A4 or equivalent paper, on one side, double spaced with margins of not less than 3.5 cm. Sheets should be numbered consecutively at the head. The top copy and two good copies should be submitted.

Papers are refereed anonymously. The author's name and address should therefore appear under the title on a separate page. The title and abstract should appear on the first page of text. Authors who wish to ascertain in advance the criteria on which submissions are judged may obtain a copy of the blank referee's form from the editors.

Tables should be typed double spaced on separate sheets, or spaced sufficiently to be distinct in the case of small tables. They should be numbered in sequence in arabic numerals and referred to in the text as 'Table 1' etc. Large tables of more than six lines should be titled in order to make the contents comprehensible independently of the text.

Diagrams, graphs, drawings and half-tone illustrations should be on a separate sheet labelled 'Fig. 1' and so forth. Each sheet should carry at the top the title of the article.

Where possible they should be submitted as artwork ready for photographic reproduction, larger than the intended size. Where more than one figure is submitted, they should be as far as possible be to the same scale. When submitting articles on disk (see below) figures should be supplied as separate TIFF or EPS files if possible.

References in the text should cite the author's name followed by the date of the publication unless there are more than two authors where only the first author's name should be given followed by 'et al.'. References should be listed at the end of the paper in alphabetical order by first author, but including all authors, in the following format with titles of articles, books and journals given in full.

BERRYMAN, J.C. and WINDRIDGE, K.C. (1993) Pregnancy after 35: a preliminary report on maternal-fetal attachment. *Journal of Reproductive and Infant Psychology*, **11**, 169-174.

BERRYMAN, J.C., THORPE, K.J. and WINDRIDGE, K.C. (1995) *Older Mothers: conception, pregnancy and birth after 35*. Pandora, London.

REID, M. (1990) Prenatal diagnosis and screening. In Garcia, J., Kilpatrick, R. and Richards, M.P.M. (Eds), *The Politics of Maternity Care*, pp. 300-324. Oxford University Press, Oxford.

SI units should be used for all measurements. Imperial measurements may be quoted in brackets. Where studies involve small numbers of subjects, both numbers and percentages of groups should be given.

Authors are advised to avoid sexist sentiments and language, except insofar as these form part of a study.

After notification of acceptance of a paper, authors should, if possible, send a copy of the final version as word-processed document on computer disk to the accepting editor.

Manuscripts and correspondence concerning publication of articles will only be kept for 3 years by the Editors.

Page proofs will be sent to the author submitting each article. Correction of typographical and other minor errors only will be permitted at this stage. Textual alterations may be charged to authors in exceptional circumstances.

Fifty offprints of each paper are supplied free to the author nominated for correspondence, for further distribution, together with a copy of the issue concerned. Additional offprints may be purchased by returning to Taylor & Francis Ltd the order form enclosed with proofs. Offprints are sent about 3 weeks after publication.

For further guidance on general aspects of manuscript preparation authors should consult APA or BPS Manuals for Contributors.

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APPENDIX 3.1

University of Glasgow, Department of Psychological Medicine

**Title: “Assessing the psychological profile of mothers
whose infants require neonatal in-patient care”**

Researchers:

Miss Deirdre Forrest, Clinical Psychologist in Training and **Dr. Elizabeth Campbell**, Consultant Clinical Psychologist, Department of Psychological Medicine, University of Glasgow.

Dr. Barbara Holland, Consultant Paediatrician, Paediatric Department, Queen Mother’s Hospital, Yorkhill NHS Trust.

Mrs Christina DelPriore, Consultant Clinical Psychologist, Head of Child Psychology Service, Yorkhill NHS Trust

Thank you very much for participating in this study. Your help is greatly appreciated.

If you want further help or feel distressed now or in the future you can contact:

1. The ward staff, who will be able to direct you to appropriate agencies.
2. Your GP, who be able to offer support and advice or make a referral to appropriate agency
3. Your hospital Consultant who will be able to give you advice about help that is available.
4. Dr. Elizabeth Campbell or Miss Deirdre Forrest at The Department of Psychological Medicine, University of Glasgow, (0141) 211 3920 who will also be able to offer you appropriate advice.

Once again anything you discuss with these professionals will be confidential.

APPENDIX 3.2

Protocol for significantly distressed mothers

Due to the nature of the area being researched a degree of distress is expected in some participants. If there appears to be real impairment to functioning and / or the interviewer judges that the participant is posing a risk to themselves or the child then this will be defined as significant distress and the following protocol will be adhered to. However, as we expect a range of distress different interventions may be appropriate for each individual. Each participant in the study will receive letter advising on who to contact should they feel distressed and in need of help or advice.

1. Letter with options for help given to all participants.
2. Immediate response would be to discuss the situation with the mother and suggest restorative self-help measures which could make an impact on their distress. For example, techniques to help reduce anxiety or increase sleep etc.
3. Discuss with the mother what help they feel they need or would like.
4. Suggest that they make contact with their GP who will be able to discuss available options. Offer to contact their GP to explain how we have found the participant to be. Through the GP facilitate referral to appropriate services.
5. Interviewer may discuss the issues with research supervisors
6. If it is deemed to be appropriate and the participant is in agreement referral to Elizabeth Campbell in her capacity as Consultant Clinical Psychologist at Stobhill Hospital could be made.

APPENDIX 3.3

University of Glasgow, Department of Psychological Medicine

INFORMATION SHEET

PRIVATE AND CONFIDENTIAL

This is an invitation to consider participation in a study which has been jointly initiated by this unit and the Department of Psychological Medicine, University of Glasgow.

Refusal to participate in this study will in no way affect your infant's or your own treatment. If you do decide to participate in this study you are entitled to pull out at any stage.

**Title: “Assessing the psychological profile of mothers
 whose infants require neonatal in-patient care”**

Researchers:

Miss Deirdre Forrest, Clinical Psychologist in Training and **Dr. Elizabeth Campbell**, Consultant Clinical Psychologist, Department of Psychological Medicine, University of Glasgow.

Dr. Barbara Holland, Consultant Paediatrician, Paediatric Department, Queen Mother's Hospital, Yorkhill NHS Trust.

Mrs Christina DelPriore, Consultant Clinical Psychologist, Head of Child Psychology Service, Yorkhill NHS Trust.

It is known that mothers react in different ways to having an infant in intensive or special care and this study will try to identify some of the factors that may contribute to

mothers developing psychological difficulties.

Although this study may not directly be of benefit to you, it is hoped that the results will provide guidance to health care professionals to further enable them to understand the needs of these mothers and offer appropriate support.

If you agree to participate in this study you will be asked to complete 2 short questionnaires and an interview whilst your child is still in hospital and 3 months later you will be sent 2 questionnaires to complete and send back. Information will also be sought from the case notes and ward staff regarding the birth and your infant's condition. A letter will be sent to your GP to inform them that you are participating in this study. All of your answers on the questionnaires and in the interview will be totally confidential.

If you have any queries about the study please contact:

Dr. Elizabeth Campbell / Miss Deirdre Forrest

Department of Psychological Medicine

Academic Centre

Gartnavel Royal Hospital

(0141) 211 3920

Dr. Barbara Holland

Paediatrics Department

Queen Mother's Hospital

Yorkhill NHS Trust

APPENDIX 3.4

Participant no. _____

University of Glasgow, Department of Psychological Medicine

CONSENT FORM

PRIVATE AND CONFIDENTIAL

Title: **“Assessing the psychological profile of mothers
 whose infants require neonatal in-patient care”**

Researchers:

Miss Deirdre Forrest, Clinical Psychologist in Training and **Dr. Elizabeth Campbell**,
Consultant Clinical Psychologist, Department of Psychological Medicine, University of
Glasgow.

Dr. Barbara Holland, Consultant Paediatrician, Paediatric Department, Queen
Mother’s Hospital, Yorkhill NHS Trust.

Mrs Christina DelPriore, Consultant Clinical Psychologist, Head of Child Psychology
Service, Yorkhill NHS Trust

I have read the information sheet (which contains a contact name and telephone
number) and the above project has been explained to me. I understand that I can choose
not to take part in the study and I can drop out at any stage. This will not affect my
child’s or my own health care.

I agree to take part in this study.

It was explained to me by _____

Signature of participant _____ Date _____

Signature of doctor _____ Date _____

Signature of witness _____ Date _____

APPENDIX 3.5**GP /CONSULTANT**

Dear Dr

Re:

The above patient has agreed to participate in the following study:

“Assessing the psychological profile of mothers whose infants require neonatal in-patient care”

Researchers:

Miss Deirdre Forrest, Clinical Psychologist in Training and **Dr. Elizabeth Campbell**, Consultant Clinical Psychologist, Department of Psychological Medicine, University of Glasgow.

Dr. Barbara Holland, Consultant Paediatrician, Paediatric Department, Queen Mother’s Hospital, Yorkhill NHS Trust.

Mrs Christina DelPriore, Consultant Clinical Psychologist, Head of Child Psychology Service, Yorkhill NHS Trust

This study hopes to determine the needs of mothers who have infants in the neonatal unit and hopefully guide future input to this group.

Data collection will include an interview and questionnaires. Each participant will be given a number and their names will be kept confidential.

If you have any queries please contact me at the above address.

Yours sincerely

Miss Deirdre Forrest

Dr Elizabeth Campbell

Trainee Clinical Psychologist

Senior Lecturer in Clinical Psychology

APPENDIX 3.6

SEMI-STRUCTURED INTERVIEW

Participant no. _____

Date of interview: _____

No. of days post delivery: _____

Thank you for participating in this study. It is known that mothers react in different ways to the difficulties they face when their newborn infant is in hospital and from this interview I hope to find out some of the factors which may contribute to the stresses mothers have to face. I will be asking you a range of questions to enable me to get a clear picture of your experience of this birth and any previous birth experiences you have had.

GENERAL

1. Age

1) <162) 16-203) 21-254) 26-305) 31-356) 36-407) >40
2. Occupation:

1) UNEMPLOYED 2) UNSKILLED 3) SKILLED 4) PROFESSIONAL
3.

(1) SINGLE(2) MARRIED(3) LIVING WITH PARTNER
4. Who is the first person you want to discuss problems with?

(1) NOBODY(2) PARTNER(3) PARENT(4) OTHER RELATIVE(5) FRIEND(6) PROFESSIONAL

Have you been able to discuss your current worries with this person? 1)YES 2) NO

5. Have there been any major events in your life over the past year e.g. new job, new house, bereavement or other upsetting events? 1) YES 2) NO

If yes, please give details

6. Have you ever seen a psychologist or psychiatrist? 1) YES 2) NO

7. Have you had a previous postpartum psychological disorder? 1)YES 2)NO

BIRTH HISTORY

8. Is this your first pregnancy 1) YES 2) NO (If yes go to question 12)

9. Have you experienced previous reproductive trauma? 1)YES 2)NO

10. Have you - 1) HAD NO PREVIOUS PREGNANCIES

2) HAD NORMAL PREGNANCIES IN THE PAST

3) HAD A PREVIOUS MISCARRIAGE

4) HAD A PREVIOUS TERMINATION

5) HAD MORE THAN ONE MISCARRIAGE

6) HAD MORE THAN ONE TERMINATION

7) HAD BOTH TERMINATION AND MISCARRIAGE

11. Do you have any other children? 1) YES 2) NO

If yes - what age are they? _____

12. Were there any complications with your previous pregnancies?

- 1) PAINS
- 2) BLEEDING
- 3) RAISED BLOOD PRESSURE
- 4) ABNORMAL SCREENING
- 5) OTHER
- 6) COMBINATION
- 7)NONE

If yes, please describe

13. Did you require hospitalisation? 1) YES 2) NO

If yes, for how long? _____

14. Were there any complications with your previous births?

- 1) PREMATURE BIRTH
- 2) FETAL DISTRESS e.g. altered heart rate
- 3) EMERGENCY CAESAREAN
- 4) STILL BIRTH / MISCARRIAGE
- 5) COMBINATION
- 6) OTHER
- 7) NONE

If yes, please describe

15. Did your infant require in-patient care? 1)YES 2) NO

PREGNANCY DETAILS

16. Was this pregnancy planned?

- 1) 100%, WAS TRYING TO GET PREGNANT
- 2) HOPED TO HAVE A BABY IN NEAR FUTURE
- 3) NOT PLANNED _____

17. Were you happy when you found out? 1) YES, VERY HAPPY

- 2) SURPRISED, BUT PLEASED
- 3) UNSURE/UNHAPPY THEN PLEASED
- 4) NOT BOTHERED
- 5) SHOCKED UPSET OR WORRIED

18. How did your partner feel?

- 1) VERY HAPPY
- 2) SURPRISED, BUT PLEASED
- 3) UNSURE/UNHAPPY THEN PLEASED
- 4) NOT BOTHERED
- 5) SHOCKED, UPSET OR WORRIED _____

19. Was your partner supportive? 1) YES, VERY

- 2) MODERATELY
- 3) NO, NOT AT ALL _____

20. Were there any complications during this pregnancy?

- 1) PAINS
- 2) BLEEDING
- 3) RAISED BLOOD PRESSURE
- 4) ABNORMAL SCREENING
- 5) OTHER
- 6) COMBINATION
- 7) NONE _____

If yes, please describe

21. Did you require hospitalisation? 1) YES 2) NO _____

If yes, for how long? _____

BIRTH DETAILS

22. Was labour induced? 1) YES 2) NO _____

23. Why? 1) POST DATE 2) PREGNANCY COMPLICATIONS 3) OTHER_____

24. How long were you in labour?

1) <3 HOURS

2) 3-6 HOURS

3) 6-10 HOURS

4) 10+ HOURS

25. At what stage of pregnancy did you give birth?

1) 42+ WEEKS 2) 37-42 WEEKS

3) 34-36 WEEKS 4) 30-33 WEEKS

5) <30 WEEKS

26. 1) FULL TERM 2) PRETERM

27. Was your partner present at the birth? 1)YES 2)NO 3)N/A _____

28. Was any friend or relative present at the birth? 1)YES 2)NO 3)N/A _____

29. Were there any complications during this birth?

- 1)PREMATURE BIRTH
- 2)FETAL DISTRESS e.g. altered heart rate
- 3)EMERGENCY CAESAREAN
- 4)COMBINATION
- 5)OTHER
- 6)NONE
-

30. Was the delivery

1)NORMAL

2)CAESAREAN

3)INSTRUMENTAL

4)BREECH

5)OTHER

31. Did you feel that your life was in danger at any stage during the birth?

- 1) YES
- 2)NO
-

If yes, please give details

32. Did you feel that your baby’s life was in danger at any stage during the birth?

- 1)YES
- 2) NO
-

If yes, please give details

33. Was the pain of birth

- 1) GREATER THAN EXPECTED
- 2) AS EXPECTED
- 3) LESS THAN EXPECTED
-

34. Did you have any pain relief?

- 1) NONE
- 2) GAS+AIR
- 3) OPIATE INJECTION
- 4) EPIDURAL
- 5) OTHER (e.g.Tens, aromatherapy) 6) COMBINATION _____

35. At what stage did you discover that your child may need in-patient care?

- 1) BEFORE THE BIRTH
- 2) DURING THE BIRTH
- 3) AFTER THE BIRTH
- 4) N/A _____

36. Given your previous history did this come as a surprise to you?

- 1) VERY MUCH SO
- 2) A LITTLE
- 3) NOT REALLY
- 4) NOT AT ALL
- 5) N/A _____

37. How prepared were you for this to happen to your child?

- 1) VERY
- 2) MODERATELY
- 3) NOT VERY
- 4) NOT AT ALL
- 5) N/A _____

38. Interviewers perception of preparedness

39. Was the birth experience? 1) POSITIVE 2) NEGATIVE 3)NEUTRAL _____

40. What did your child weigh when he/she was born?

- 1)2500g+ (normal birth weight)
- 2)<2500g / 5.5lb (low birth weight)
- 3)<1500 / 3.5lb (very low birth weight)
- 4)<1000g/ 2.2lb (extremely low birth weight) _____

Which of the following words describes your feelings:

- 41. during pregnancy _____
- 42 during labour _____
- 43. during delivery _____
- 44. immediately after delivery _____
- 45. now _____

- | | | | |
|--------------|-------------------|----------|----------------|
| 1)WORRIED | 2)NERVOUS | 3)HAPPY | 4)EXCITED |
| 5)SAD | 6)UNHAPPY | 7)SCARED | 8)INVOLVED |
| 9)CONFIDENT | 10)IN CONTROL | 11)CALM | 12)OVERWHELMED |
| 13)POWERLESS | 14)OUT OF CONTROL | | |

Details _____

- 46. Was your pregnancy _____
- 47. Was labour _____
- 48. Was the delivery _____
- 49. Immediately after delivery _____
- 50. How do you feel now? _____

- 1) BETTER THAN 2) WORSE THAN 3) SAME AS EXPECTED

Have any of the following upset you whilst in the unit:

51. The appearance of your child e.g. colour, size 1)YES 2)NO _____

52. Aspects of your child's treatment e.g. tubes / injections 1)YES 2)NO _____

53. Equipment used in your child's treatment e.g. incubator 1)YES 2)NO _____

54. Seeing your baby in pain, crying, having trouble breathing 1)YES 2)NO _____

55. Not being able to care for your child 1)YES 2)NO _____

56. Separation from your child 1)YES 2)NO _____

57. Being scared to hold your child 1)YES 2)NO _____

56. Mother's perceived outcome for child 1)very poor 2)poor 3)moderate 4)good
5)don't know _____

57. Mother's perception of birth

1)traumatic 2)unpleasant 3)neutral

4)pleasant 5)extremely pleasant_____

58. Interviewers perception of birth

APPENDIX 4.1

Journal of Reproductive and Infant Psychology

Notes for Contributors

Journal of Reproductive and Infant Psychology welcomes reports of original research and creative or critical review articles which make an original contribution. Articles should not currently be submitted for publication elsewhere.

Topics of interest to the journal include medical, behavioural, cognitive, affective, dynamic, psychological, societal and social aspects of: fertility and infertility; menstruation and menopause; pregnancy and childbirth; antenatal preparation; motherhood and fatherhood; neonatology and early infancy; infant feeding; early parent-child relationships; postnatal psychological disturbance and psychiatric illness; obstetric and gynaecology including preparation for medical procedures; psychology of women.

The journal also publishes brief reports, comment articles and special issues dealing with innovative and controversial topics. A review section reports on new books and training material.

Studies of both human and animal subjects are welcome.

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Suzanne Zeedyk, Department of Psychology, The University of Dundee, Dundee, DD1 4HN, UK;

Ken Gannon, St Bartholomew's & The Royal London School of Medicine and Dentistry, School of Occupational Therapy, Turner Street, London E1 2AD, UK;

John Worobey, Department of Nutritional Sciences, Rutgers University, Turner Street, London E1 2AD, UK;

Mechthild Papousek, Institute for Social Pediatrics and Youth Medicine, University of Munich, Heiglhofstr.63, D-81377 Munich, Germany

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Papers should be typed on A4 or equivalent paper, on one side, double spaced with margins of not less than 3.5 cm. Sheets should be numbered consecutively at the head. The top copy and two good copies should be submitted.

Papers are refereed anonymously. The author's name and address should therefore appear under the title on a separate page. The title and abstract should appear on the first page of text. Authors who wish to ascertain in advance the criteria on which submissions are judged may obtain a copy of the blank referee's form from the editors.

Tables should be typed double spaced on separate sheets, or spaced sufficiently to be distinct in the case of small tables. They should be numbered in sequence in arabic numerals and referred to in the text as 'Table 1' etc. Large tables of more than six lines should be titled in order to make the contents comprehensible independently of the text.

Diagrams, graphs, drawings and half-tone illustrations should be on a separate sheet labelled 'Fig. 1' and so forth. Each sheet should carry at the top the title of the article.

Where possible they should be submitted as artwork ready for photographic reproduction, larger than the intended size. Where more than one figure is submitted, they should be as far as possible be to the same scale. When submitting articles on disk (see below) figures should be supplied as separate TIFF or EPS files if possible.

References in the text should cite the author's name followed by the date of the publication unless there are more than two authors where only the first author's name should be given followed by 'et al.'. References should be listed at the end of the paper in alphabetical order by first author, but including all authors, in the following format with titles of articles, books and journals given in full.

BERRYMAN, J.C. and WINDRIDGE, K.C. (1993) Pregnancy after 35: a preliminary report on maternal-fetal attachment. *Journal of Reproductive and Infant Psychology*, **11**, 169-174.

BERRYMAN, J.C., THORPE, K.J. and WINDRIDGE, K.C. (1995) *Older Mothers: conception, pregnancy and birth after 35*. Pandora, London.

REID, M. (1990) Prenatal diagnosis and screening. In Garcia, J., Kilpatrick, R. and Richards, M.P.M. (Eds), *The Politics of Maternity Care*, pp. 300-324. Oxford University Press, Oxford.

SI units should be used for all measurements. Imperial measurements may be quoted in brackets. Where studies involve small numbers of subjects, both numbers and percentages of groups should be given.

Authors are advised to avoid sexist sentiments and language, except insofar as these form part of a study.

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publisher, Society for Reproductive and Infant Psychology, provided that acknowledgement is given to the Journal as the original source of publication, and that Carfax is notified so that our records show that its use is properly authorised.

APPENDIX 4.2

DEMOGRAPHIC DETAILS ABOUT MOTHERS:

Age	16-20years	8%
	21-25years	17%
	26-30years	26%
	31-35years	36%
	36+years	13%
Occupational Status	Unemployed	19%
	Unskilled	26%
	Skilled	28%
	Professional	27%
Marital Status	Married	72%
	Co-habiting	17%
	Single	11%
Number of children	0	55%
	1	32%
	2	7%
	3	2%
	4	2%
	5	0%
	6	0%
	7	2%
Social support	Yes	91%
	No	9%
Life Events	Yes	68%
	No	32%
Seen psychologist previously	Yes	26%
	No	74%
Previous postnatal Distress	Yes	40%
	No	23%
	N/A	47%

APPENDIX 4.3

INFANT CHARACTERISTICS AND QUESTIONNAIRE SCORES

Figure 1: Infant gestational age and questionnaire scores

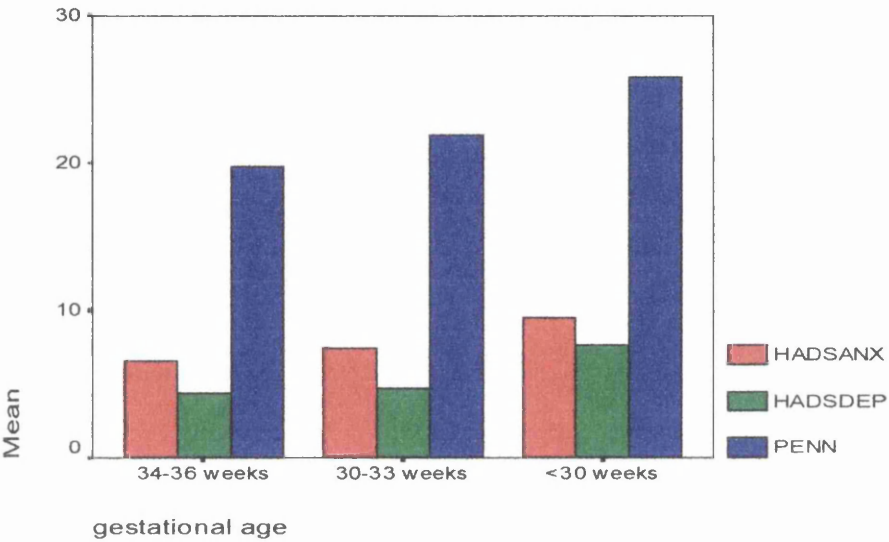
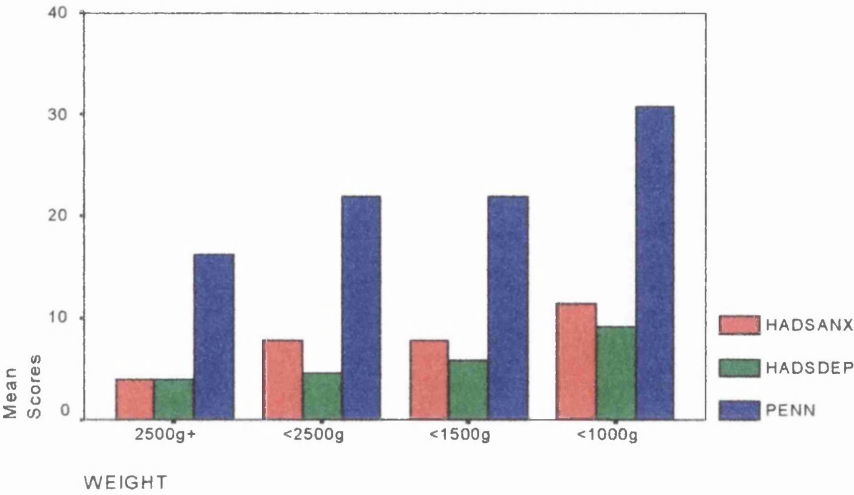


Figure 2: Infant weight and questionnaire scores



APPENDIX 4.4

SYMPTOM PROFILE

Figure 1: Profile of mothers who reached diagnostic criteria for any DSM-IV diagnosis.

	Yes
Child in intensive care initially	100%
Life events	82%
Previously seen psychologist	45%
Primiparous	18%
Previous birth distress (multiparous women)	54%
No children	36%
In-patient stay while pregnant	73%
Infant stay 40+ days	54%
Pregnancy complications	82%
Caesarian Section	82%
General Anaesthetic	18%
Surprised	82%
Knew before the birth about complications	82%
Negative birth experience	54%
Ventilated	73%
Perceived birth as traumatic experience	45%
Prepared	27%
Multiple birth	27%
Gestation <30 weeks	64%

APPENDIX 4.5

MOTHERS’ PERCEPTIONS OF THE EXPERIENCE

Mothers described their feelings during their pregnancy, labour and birth, immediately after the birth and at the time of interview choosing words from a list presented to them. The results are shown in the following table.

Table 1: Words mothers used to describe the stages of their experience

	Pregnancy	Labour + Birth	Immediately after the birth	At time of interview
Worried	62%	49%	57%	47%
Nervous	57%	47%	40%	40%
Sad	9%	6%	15%	11%
Unhappy	7.5%	6%	13%	6%
Scared	30%	43%	38%	17%
Overwhelmed	21%	24.5%	34%	26%
Powerless	15%	32%	43%	13%
Horror	2%	13%	6%	0%
Helpless	15%	30%	60%	15%
Out of control	26%	41.5%	53%	21%
Worried they or their child may be injured or ill	28%	49%	66%	36%
Worried they or the child may die	28%	47%	57%	26%
Fearful	21%	30%	23%	9%
Happy	89%	19%	70%	74%
Excited	68%	32%	36%	49%
Calm	62%	36%	26%	36%
In control	60%	17%	11%	49%
Involved	66%	17%	13%	57%
Confident	53%	19%	26%	40%

APPENDIX 4.6

COMPARING UNITS

Table 1: Neonatal unit and infant gestational age

	34-36wks	30-33wks	<30wks	Total
SCBU	7 (13%)	3 (6%)	0 (0%)	10 (19%)
ITU	11 (21%)	18 (34%)	14 (26%)	43 (81%)
Total	18 (34%)	21 (40%)	14 (26%)	53 (100%)

Table 2: Neonatal unit and infant birth weight

	2500+g	<2500g	<1500g	<1000g
SCBU	3 (6%)	7 (13%)	0	0
ITU	5(9.5%)	17(32%)	14(26.5%)	7(13%)
Total	8(15.5%)	24(45%)	14(26.5%)	7(13%)

Table 3: Birth and postnatal characteristics

	ITU	SCBU	Total
Ventilated	30	0	30
Caesarian Section	34	5	39
General Anaesthetic	6	1	7
Multiple birth	8	0	8

APPENDIX 4.7

**Table 1: Frequencies of mothers reporting distress about factors related to
situation**

	ITU	SCBU	Total
Appearance / size	13 (24%)	2 (4%)	15 (28%)
Not being able to care for child	39 (74%)	7 (13%)	46 (87%)
Being separated from child	41 (77%)	6 (11%)	47 (89%)
Crying	27 (51%)	6 (11%)	33 (62%)
Equipment used	16 (30%)	2 (4%)	18 (34%)
Treatment used	27 (51%)	3 (6%)	30 (57%)

APPENDIX 4.8

PENN INVENTORY

1/90N26

Name _____

Date _____

In this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling during the **PAST WEEK, INCLUDING TODAY!** Circle the number beside the statement you picked. Be sure to read all the statements in each group before making your choice.

- 0 I don't feel much different than most other people my age.
 - 1 I feel somewhat different than most other people my age.
 - 2 I feel so different than most other people my age that I choose pretty carefully who I'll be with and when.
 - 3 I feel so totally alien to most other people my age that I stay away from all of them at all costs.
- 2 0 I care as much about the consequences of what I'm doing as most other people.
 - 1 I care less about the consequences of what I'm doing than most other people.
 - 2 I care much less about the consequences of what I'm doing than most other people.
 - 3 Often I think, "Let the consequences be damned!" because I don't care about them at all.
- 3 0 When I want to do something for enjoyment I can find someone to join me if I want to.
 - 1 I'm able to do something for enjoyment even when I can't find someone to join me.
 - 2 I lose interest in doing things for enjoyment when there's no one to join me.
 - 3 I have no interest in doing anything for enjoyment at all.
- 4 0 I rarely feel jumpy or uptight.
 - 1 I sometimes feel jumpy and uptight.
 - 2 I often feel jumpy or uptight.
 - 3 I feel jumpy or uptight all the time.
- 5 0 I know someone nearby who really understands me.
 - 1 I'm not concerned whether anyone nearby really understands me.
 - 2 I'm worried because no one nearby really understand me.
 - 3 I'm very worried because no one nearby understands me at all.
- 6 0 I'm not afraid to show my anger because it's no worse or better than anyone else's.
 - 1 I'm sometimes afraid to show my anger because it goes up quicker than other people's.
 - 2 I'm often afraid to show my anger because it might turn to violence.
 - 3 I'm so afraid of becoming violent that I never allow myself to show any anger at all.
- 7 0 I don't have any past traumas to feel overly anxious about.
 - 1 When something reminds me of my past traumas I feel anxious but can tolerate it.
 - 2 When something reminds me of my past traumas I feel very anxious and must really make an effort to tolerate it.
 - 3 When something reminds me of my past traumas I feel so anxious I can hardly stand it and have no ways to tolerate it.
- 8 0 I have not re-experienced a flashback to a trauma event "as if I were there again."
 - 1 I have re-experienced a flashback to a trauma event "as if I were there again" for a few minutes or less.
 - 2 My re-experiencing of a flashback to a trauma event sometimes lasts the better part of an hour.
 - 3 My re-experiencing of a flashback to a trauma event often lasts for an hour or more.
- 9 0 I am less easily distracted than ever.
 - 1 I am as easily distracted as ever.
 - 2 I am more easily distracted than ever.
 - 3 I feel distracted all the time.
- 10 0 My spiritual life provides more meaning than it used to.
 - 1 My spiritual life provides about as much meaning as it used to.
 - 2 My spiritual life provides less meaning than it used to.
 - 3 I don't care about my spiritual life.
- 11 0 I can concentrate better than ever.
 - 1 I can concentrate about as well as ever.
 - 2 I can't concentrate as well as I used to.
 - 3 I can't concentrate at all.
- 12 0 I've told a friend or family member about the important parts of my most traumatic experiences.
 - 1 I've had to be careful in choosing the parts of my traumatic experiences to tell friends or family members.
 - 2 Some parts of my traumatic experiences are so hard to understand that I've said almost nothing about them to anyone.
 - 3 No one could possibly understand the traumatic experiences I've had to live with.
- 13 0 I generally don't have nightmares.
 - 1 My nightmares are less troubling than they were.
 - 2 My nightmares are just as troubling as they were.
 - 3 My nightmares are more troubling than they were.
- 14 0 I don't feel confused about my life.
 - 1 I feel less confused about my life than I used to.
 - 2 I feel just as confused about my life as I used to.
 - 3 I feel more confused about my life than I used to.
- 15 0 I know myself better than I used to.
 - 1 I know myself about as well as I used to.
 - 2 I don't know myself as well as I used to.
 - 3 I feel like I don't know who I am at all.

(Please continue on the reverse side)

- 16 0 I know more ways to control or reduce my anger than most people.
 1 I know about as many ways to control or reduce my anger as most people.
 2 I know fewer ways to control or reduce my anger than most people.
 3 I know of no ways to control or reduce my anger.
- 17 0 I have not experienced a major trauma in my life.
 1 I have experienced one or more traumas of limited intensity.
 2 I have experienced very intense and upsetting traumas.
 3 The traumas I have experienced were so intense that memories of them intrude on my mind without warning.
- 18 0 I've been able to shape things toward attaining many of my goals.
 1 I've been able to shape things toward attaining some of my goals.
 2 My goals aren't clear.
 3 I don't know how to shape things toward my goals.
- 19 0 I am able to focus my mind and concentrate on the task at hand regardless of unwanted thoughts.
 1 When unwanted thoughts intrude on my mind I'm able to recognize them briefly and then refocus my mind on the task at hand.
 2 I'm having a hard time coping with unwanted thoughts and don't know how to refocus my mind on the task at hand.
 3 I'll never be able to cope with unwanted thoughts.
- 20 0 I am achieving most of the things I want.
 1 I am achieving many of the things I want.
 2 I am achieving some of the things I want.
 3 I am achieving few of the things I want.
- 21 0 I sleep as well as usual.
 1 I don't sleep as well as usual.
 2 I wake up more frequently or earlier than usual and have difficulty getting back to sleep.
 3 I often have nightmares or wake up several hours earlier than usual and cannot get back to sleep.
- 22 0 I don't have trouble remembering things I should know.
 1 I have less trouble than I used to remembering things I should know.
 2 I have about the same trouble as I used to remembering things I should know.
 3 I have more trouble than I used to remembering things I should know.
- 23 0 My goals are clearer than they were.
 1 My goals are as clear as they were.
 2 My goals are not as clear as they were.
 3 I don't know what my goals are.
- 24 0 I'm usually able to let bad memories fade from my mind.
 1 Sometimes a bad memory comes back to me, but I can modify it, replace it, or set it aside.
 2 When bad memories intrude on my mind I can't seem to get them out.
 3 I worry that I'm going crazy because bad memories keep intruding on my mind.
- 25 0 Usually I feel understood by others. 154
 1 Sometimes I don't feel understood by others.
 2 Most of the time I don't feel understood by others.
 3 No one understands me at all.
- 26 0 I have not lost anything or anyone dear to me.
 1 I have grieved for those I've lost and can now go on.
 2 I haven't finished grieving for those I've lost.
 3 The pain of my loss is so great that I can't grieve and don't know how to get started.

Name _____ Date _____

On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling during the **PAST WEEK, INCLUDING TODAY!** Circle the number beside the statement you picked. Be sure to read all the statements in each group before making your choice.

- 1 0 I don't feel much different than most other people my age.
1 I feel somewhat different than most other people my age.
2 I feel so different than most other people my age that I choose pretty carefully who I'll be with and when.
3 I feel so totally alien to most other people my age that I stay away from all of them at all costs.
- 2 0 I care as much about the consequences of what I'm doing as most other people.
1 I care less about the consequences of what I'm doing than most other people.
2 I care much less about the consequences of what I'm doing than most other people.
3 Often I think, "Let the consequences be damned!" because I don't care about them at all.
- 3 0 When I want to do something for enjoyment I can find someone to join me if I want to.
1 I'm able to do something for enjoyment even when I can't find someone to join me.
2 I lose interest in doing things for enjoyment when there's no one to join me.
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1 I sometimes feel jumpy and uptight.
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- 5 0 I know someone nearby who really understands me.
1 I'm not concerned whether anyone nearby really understands me.
2 I'm worried because no one nearby really understand me.
3 I'm very worried because no one nearby understands me at all.
- 6 0 I'm not afraid to show my anger because it's no worse or better than anyone else's.
1 I'm sometimes afraid to show my anger because it goes up quicker than other people's.
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- 7 0 I don't have any past traumas to feel overly anxious about.
1 When something reminds me of my past traumas I feel anxious but can tolerate it.
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3 I can't concentrate at all.
- 12 0 I've told a friend or family member about the important parts of my most traumatic experiences.
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2 Some parts of my traumatic experiences are so hard to understand that I've said almost nothing about them to anyone.
3 No one could possibly understand the traumatic experiences I've had to live with.
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2 My nightmares are just as troubling as they were.
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2 I feel just as confused about my life as I used to.
3 I feel more confused about my life than I used to.
- 15 0 I know myself better than I used to.
1 I know myself about as well as I used to.
2 I don't know myself as well as I used to.
3 I feel like I don't know who I am at all.

(Please continue on the reverse side)

APPENDIX 4.9



YORKHILL NHS TRUST

EM/



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Organisational Audit.

Our Ref.

Your Ref.

Direct Dial No.
7 April 1999

Miss Deirdrie Forrest
Department of Psychological Medicine
University of Glasgow
Yorkhill NHS Trust
Glasgow

Dear Miss Forrest

P14/99 Assessing the psychological profile of mothers whose infants require in patient neonatal care.

Thank you for submitting your proposal to the Yorkhill Ethics Committee. This was discussed at the meeting of 1 April 199 and approved subject to :

- 1) Subjects should be informed that information will be sought from ward staff
- 2) lay terms should be used throughout the semi structured interview.
- 3) appendix 8 page 20 omit 'refusal' insert 'if you do not wish to participate'
- 4) members asked if you had considered the practicalities of the recruitment of the control group
- 5) GP's should be informed of the study and copies of appendix 8 should be sent to them
- 6) ward staff should be given a copy of appendix 8

One copy of your amendments forwarded to me will be sufficient.

I look forward to your reply.

With kind regards

Yours sincerely

Dr N Morton
Vice Chairman Yorkhill Ethics Committee

Dept. of Psychological Medicine
University of Glasgow
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
G12 0XH

2nd June 1999

Dear Dr Morton

P14/99 Assessing the psychological profile of mothers whose infants require in-patient neonatal care.

Further to your letter dated 7th April 1999 I enclose a copy of the suggested amendments.

- 1) Subjects will be informed that information will be sought from ward staff and this is included in Appendices 5 and 6.
- 2) The semi-structured interview has been altered to include lay terms (a copy is enclosed). I must, however, stress that this interview will not be conducted using a rigid format and questions will not be asked in the mechanical manner they are set out in.
- 3) Appendices 5 and 6 have been changed. The word "refusal" has been omitted and the phrase "if you do not wish to participate" has been inserted as suggested.
- 4) In conducting this study we are hoping that there will be sufficient variation within the hospital sample to allow us to address the study questions without a control group. If we do need to recruit a control group we anticipate having to liaise with the obstetricians at the hospital. If this need arises we will give the Ethics Committee sight of any proposed recruitment strategy.
- 5) GPs are to be informed of the study and copies of Appendix 8 will be sent to them, as requested.
- 6) Ward staff will be given a copy of Appendix 8, as requested.

I trust that these amendments are in order. I hope that data collection can start in the near future and in the meantime I have arranged to meet with Dr Holland to discuss the practicalities of carrying out the study.

Yours sincerely

Deirdre Forrest
Trainee Clinical Psychologist

CLINICAL RESEARCH CASE STUDY ABSTRACT

Multicomponent treatment for chronic insomnia:

A single case study

Deirdre Forrest
Trainee Clinical Psychologist
Department of Psychological Medicine
Gartnavel Royal Hospital
Glasgow
G12 0XH

Word count: 3081

Running head: Multicomponent treatment for insomnia

ABSTRACT

This study aimed to examine the efficacy of a multicomponent intervention for chronic insomnia. It was a single subject design with a multiple baseline and multiple treatment components. The participant was a 30-year old male with chronic sleep difficulties, poor sleep efficiency, an average sleep onset of 1 hour and average sleep time per night of 4 hours. The intervention consisted of a 6-session multicomponent treatment including education, sleep hygiene, sleep scheduling and cognitive control. It was hypothesised that the sleep scheduling component would have the greatest impact. The results showed that sleep onset and wake time after onset decreased and sleep efficiency and total sleep time increased. The sleep scheduling component showed the greatest benefits. It was concluded that multicomponent treatment was successful in decreasing sleep onset latency and wake time after sleep onset and increasing sleep efficiency and total sleep time.

(143)

Keywords: Chronic insomnia, multicomponent treatment, single subject design, non-pharmacological treatment.

