

# Posttraumatic stress disorder and the NICU graduate mother

The birth of a premature baby represents a time of significant psychological stress for parents. Maternal psychological discord can severely impact on a baby's cognitive and emotional development, interrupt the parent-infant bonding process and indirectly affect patient care and outcomes. This paper will describe posttraumatic stress disorder and its associated symptoms, look at the evidence for this condition among mothers of premature infants and outline the implications and recommendations for clinical practice.

## Cathy P Ringland

RN, Paed Cert, Dip Neonatal Nursing  
Newborn Intensive Care Follow-up Clinic  
Co-ordinator  
The Department of Neonatology  
The Canberra Hospital,  
Canberra, Australia  
cathy.ringland@act.gov.au

The psychological strain and emotional stresses associated with the birth and hospitalisation of a premature baby have long been recognised<sup>1,2</sup>. Anxiety and apprehension are expected emotional responses for mothers whose babies are admitted to the neonatal intensive care unit (NICU)<sup>3</sup>. Mothers are fearful of their baby's fragile appearance, often trying to cope with their baby's uncertain survival and the potential for long-term negative outcomes for their child<sup>1,4,5</sup>. These fears can have a negative impact on the parent-infant bonding process that creates the foundation for a lifelong relationship<sup>4,6</sup>.

Independent of the baby's health status both during and after NICU hospitalisation, research supports the belief that maternal psychological wellbeing can impact on the baby's cognitive and emotional development. Maternal distress may place the child at greater risk of developmental disturbances, such as feeding, sleeping and behavioural problems<sup>1,3,4,7,8</sup>. Maternal psychological wellbeing can also indirectly affect patient care and outcomes, which in turn can have economic implications for healthcare facilities<sup>9</sup>.

A mother's ability to cope with the emotional stresses associated with the NICU environment varies from person to person<sup>4</sup>. Several studies have focused on the relationship between maternal personal characteristics, demographic variables, personal resources and the mother's level of depressive symptoms. Results to date have been mixed, though there are some consistent themes related to increased maternal distress, such as limited

emotional support, lower socioeconomic groups, minimal educational status<sup>3,4,6</sup>. Regardless, it has been well established that mothers of premature babies are at greater risk of developing significant emotional distress, particularly anxiety and depression, than mothers of term infants<sup>1,3</sup>. Research has focused on many of the issues relating to parenting premature infants during their initial hospitalisation<sup>7</sup>. Increased efforts by health professionals to identify perinatal anxiety-provoking events, triggered by having a baby in the NICU, have addressed some of the issues that can lead to maternal psychological distress.

O'Brien et al, cited in Mew et al<sup>3</sup>, state that "little progress has been made in identifying mothers of premature infants who may be at particular risk for psychological difficulties". Much of the available literature examines the psychological effects using concepts of stress<sup>1,10,11</sup>. Holditch-Davis et al argue that "the extreme distress that many mothers experience after the birth of a premature infant and NICU hospitalisation may have characteristics similar to a posttraumatic stress response"<sup>1</sup>.

The purpose of this paper is to briefly describe the signs and symptoms of posttraumatic stress disorder (PTSD), supported by descriptive accounts drawn from personal observation in a newborn intensive care follow-up clinic setting based in Canberra, Australia. This article will briefly review the available tools for assessing PTSD and highlight the implications for clinical practice and scope for future formal research to be undertaken.

## Keywords

posttraumatic stress disorder; maternal psychological wellbeing; premature infant; neonatal intensive care; trauma; maternal anxiety; stress

## Key points

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1. Maternal psychological wellbeing can impact on neonatal development.
2. Posttraumatic stress disorder can last for many years and its associated impairment and societal costs are comparable to other serious chronic mental illnesses.
3. This paper provides an insight into the trauma experienced by NICU graduate mothers.
4. It assists health professionals in identifying mothers at risk of the development of PTSD and makes recommendations for clinical practice.

## Posttraumatic stress disorder

PSTD, which was first introduced as a diagnosis in 1980<sup>12</sup>, is defined by the American Psychiatric Association as:

“a psychological disorder that follows exposure to a traumatic event involving the threat of death or serious injury to the individual or another accompanied by feelings of horror, helplessness, or intense fear”<sup>11</sup>

Women are affected twice as often as men<sup>12</sup>. Figures from the USA estimate that on average a person with PTSD will suffer 20 years of active symptoms, will experience work impairment one day a week and the annual productivity loss is estimated at \$3 billion dollars. Alarmingly the rates of attempted suicide are as high as 19%<sup>12</sup>. Four symptom clusters are described and include<sup>1,12</sup>:

- recurrent re-experiencing of the trauma
- phobic avoidance of reminders and trauma-related situations
- emotional numbing of responses
- hyperarousal

It is thought that PTSD originates because of a need to gain mastery over a terrifying event – the event is so terrifying that the person is unable to process the experience<sup>13</sup>.

Symptoms usually occur within three months of the traumatic event and PTSD can contribute to numerous physical and psychological symptoms<sup>1</sup>. One mother the author observed returning for her baby's follow-up appointment, was found hyperventilating in a stairwell clutching the railing unable to move. Other mothers the author has been involved with stated they felt unable to return to the NICU or became distressed when attempting to do so. Yet another avoided attending appointments altogether citing many unsubstantiated reasons. The same mother was unable to visit her ill father in hospital because of the sheer distress she reported she experienced returning to the hospital. Disturbingly, several of the mothers observed are still experiencing distressing symptoms at their child's three year visit. One NICU graduate mother expresses her ongoing trauma in a book written to assist parents adjust to the birth of a premature baby<sup>13</sup>:

“Periodically, I resolve to meet my challenges from a positive, upbeat point of view. Intellectually, cognitively, I understand that's the right way, the best way to look at things. But there is

something else at a darker, deeper emotional level that won't cooperate with my resolve. I wake up in the middle of the night aware of terrible danger. I don't know what will happen or when, I just sense it out there. And I lie awake, trying to think of how to keep it from coming, what to do, how to protect.

In the cold morning light, I think I understand that somehow I am trying to relive, to correct what happened to us all nearly five years ago. But that understanding doesn't stop the terror resting just underneath, the terror that wakes me alone and unequal to its terrible force<sup>13,19</sup>.

PTSD is distinct from acute stress disorder (ASD) which is the form of trauma that is experienced in the first few weeks to one month after the event. ASD is considered to be a forerunner to PTSD – some mothers may suffer both<sup>9,14,15</sup>.

## Background

The symptoms described in PTSD have been observed in a concerning number of the mothers attending a newborn intensive care follow-up clinic. The purpose of the clinic is to monitor outcomes for benchmarking. During the review there is usually time to have an informal chat with the mothers. Enquires are made regarding how they are getting along and some general questions are asked about whether they have been back to visit the NICU. This frequently leads to the affected mothers expressing feelings of anxiety and in some cases significant distress relating to their time spent in the NICU. A comment not infrequently heard is “I think about what we went through every day”. Assessment by a multidisciplinary team is offered to children up to three years corrected age, enabling on-going contact with these families.

Initially when some worrying psychological symptoms were observed in a number of the mothers attending the clinic, interstate peers at other tertiary hospitals were contacted to establish if they were observing similar effects. Several acknowledged they were seeing similar symptoms but that no formal data collection, identification or trauma-preventative psychological intervention programmes had been implemented. Some centres have parent groups and provide on-going support through their follow-up clinic<sup>16</sup>.

## Impact of trauma

There has been increasing recognition that family members who witness the threat to

life or integrity of a loved one can experience significant trauma as a result<sup>9</sup>. Moreover, it is only recently that research has focused on the traumatisation of parents by the premature birth of their baby<sup>13,15</sup>. In a retrospective cross-sectional cohort study involving 34 mothers of paediatric critical care patients, 18% exhibited clinically significant levels of posttraumatic stress eight months after their child's discharge from paediatric intensive care (PICU)<sup>9</sup>.

Apart from the small sample size, study inadequacies were readily acknowledged by the author in the form of a low response rate. The low rate may have been attributable to ethics restrictions prohibiting the researchers from making a follow-up phone call after the initial letter was sent, which might perhaps have resulted in an improved response rate<sup>9</sup>. Nevertheless, two recent studies of PICU parents, which had better response rates, reported similar rates of psychological distress<sup>9,17,18</sup>. Pierrehumbert et al examined the impact of perinatal risks on posttraumatic reactions of the parents<sup>8</sup>. They concluded that parents of premature infants had a higher incidence of posttraumatic reaction, “the severity of the perinatal risk increased the likelihood of the parents developing posttraumatic stress reactions”<sup>8</sup>. A previous report by DeMier et al<sup>19</sup> supports this finding, demonstrating that the incidence of PTSD symptoms displayed by mothers correlated well with the degree of postnatal complications experienced by the baby<sup>20</sup>. However this finding was not always consistent with some of the author's observations. In a larger study which used the Impact of Event Scale (IES) to determine parental trauma after premature birth, 77% of mothers showed significant psychological trauma at one month after birth and disturbingly, 49% still showed significant symptoms one year later<sup>11</sup>.

## Screening tools

Numerous psychiatric screening tools exist that may be utilised to ascertain maternal psychological wellbeing. In many of the studies reviewed some tools were used in conjunction with others to accurately assess maternal psychological distress. In the scope of this review it would be impossible to address all available psychiatric screening tools.

**TABLE 1** lists the tools most commonly referred to in the literature.

Assessment tool	Item number	Measures	Responses
Parental Stressor Scale: NICU (PSS: NICU)	28 item	Parental stress related to the NICU, affect of the altered parental role, the child's appearance and behaviour and the unit sights and sounds <sup>5</sup> .	Rated on a 5 point scale ranging from 1 (not at all stressful) to 5 (extremely stressful). Higher stress is indicated by a higher score <sup>5</sup> . (This assessment tool has consistently shown strong reliability and validity) <sup>21</sup> .
Impact of Event Scale (IES)	15 item self report	Measure of specific responses to trauma <sup>9</sup> .	Answers range from 0 (not at all) to 5 (often). A score of greater than 35 indicates a high risk of PTSD <sup>9</sup> .
PTSD questionnaire (PPQ)	14 item retrospective screening tool	Specifically designed for parents of high risk infants to assess the presence of traumatic recollections about delivery <sup>8,22</sup> .	Identifies symptoms which appeared since the birth and lasted for more than a month <sup>9</sup> . Items relate to invasive memories, avoidance and more general PTSD symptoms <sup>8</sup> .
The State – Trait Anxiety Inventory Y (STAI-Y)	Consists of 40 statements which refer to various emotional states <sup>7</sup> .	A useful basis to establish levels of anxiety in mothers <sup>7</sup> .	Twenty of the statements relate to the individual's feelings of nervousness, apprehension and worry. The other 20 relate to the individual's personality traits or how the person usually feels <sup>7</sup> .

**TABLE 1** Screening tools to ascertain levels of stress and trauma.

## Mothers at risk

Informal identification of mothers who may be at risk of the development of PTSD should not be underestimated. Undoubtedly, there are a group of mothers who are at significant risk of the development of PTSD. This group includes, those who have pre-existing anxiety or depression and those who have had previous exposure to a trauma, such as reproductive losses or have suffered sexual and/or physical abuse<sup>1,23,24</sup>. Those working in the NICU also need to be concerned and diligent about mothers who are exhibiting signs of depressive symptoms, denial, avoidance and those who are reporting greater than expected stress about the NICU<sup>1</sup>. Symptoms should not be ignored however mild they may appear<sup>13</sup>.

## Recommendations for clinical practice and scope for future research

In order for intervention programmes that specifically address the psychological needs of mothers in the NICU environment to be effective, the scope of treatment needs to focus beyond the infant and beyond the NICU<sup>20</sup>. Many gaps exist in the current knowledge of effective treatment of PTSD<sup>12</sup>. Pharmacotherapy is indicated in some individuals but remains controversial<sup>12,13</sup>. Psychosocial treatment must address three essential factors in the successful processing of traumatic events. These include emotional engagement with the traumatic memory, organisation of the trauma story and correction of dysfunctional thoughts<sup>12</sup>. In keeping with the foundation of evidence-based care informal support has little place. There is however some evidence that simple

interventions, such as follow-up clinics, diaries/journals and family conferences can significantly reduce the impact of trauma on relatives<sup>19</sup>. Simply giving mothers the opportunity at the time of admission to talk about their feelings, followed up with a phone call after discharge to see how families are getting along, can be helpful<sup>9</sup>. However although debriefing after trauma may be helpful in coping with the acute stress, it has not convincingly shown to be effective on its own to prevent the development of PTSD<sup>12</sup>.

Education about normative reactions to the trauma of having a baby in the NICU can be helpful<sup>1</sup>. Explaining to mothers that their reaction is a very normal response to an abnormal and stressful situation is valuable. One mother whose baby was in the Newborn Intensive Care Follow-up Clinic Program responded to such an explanation by saying “thank goodness for that, I thought I was going mad”.

Partnering in providing care of the infant can enhance maternal feelings of usefulness and deter the use of avoidance<sup>1,25</sup>. “Buddy” programmes, whereby NICU graduate mothers provide peer support, primarily by phone, have been evaluated and found to be effective<sup>2</sup>. Formal intervention by a trained psychologist undoubtedly has a place in the management of these mothers at risk of developing PTSD. This is supported by an evaluation of a trauma-preventative psychological intervention by Jotzo and Poets. They compared a control group of mothers who did not receive psychological intervention to a study group who actively received psychological support in the first

few days of their infant's NICU admission and throughout their stay at critical periods<sup>11</sup>. The authors concluded that at discharge the intervention group of mothers showed significantly lower levels of traumatisation.

This intervention included hospital personnel and also extended to the inclusion of the local medical officer, community nurses and social workers<sup>11</sup>. Perhaps within current services that are offered to families, early discharge programmes and follow-up clinics, addressing the ongoing psychological needs of these mothers, should become an integral part of the multidisciplinary assessment.

There is plenty of scope for research in this area, for example a large cohort study extending over a few years. Available trauma screening tools could be utilised during the antenatal and postnatal periods.

## Conclusion

Ensuring mothers' psychological wellbeing has a significant economic benefit and indirectly improves patient care and outcomes<sup>9</sup>. Initially in this review an attempt was made to separate out the admission and discharge psychological experiences. It quickly became apparent however that the impact of the trauma experienced by these mothers in the initial period of their baby's admission to the NICU continued to be felt long after their baby's discharge.

Symptoms of traumatisation can become chronic, seriously affecting quality of life. Thus early detection of mothers in the NICU at risk of the development of PTSD and prompt intervention are essential<sup>11</sup>.

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