

## **Post-traumatic Symptomatology in Parents with Premature Infants: A Systematic Review of the Literature**

**Athanasios Karatzias, PhD<sup>1</sup>, Zoë Chouliara, PhD<sup>2</sup>, Fiona Maxton, PhD<sup>3</sup>, Yvonne Freer, PhD<sup>4</sup>, and Kevin Power, PhD<sup>5</sup>**

**ABSTRACT:** The emotional distress resulting from the experience of giving birth to a preterm infant (gestational age < 37 weeks) and the subsequent neonatal unit hospitalisation may be a traumatic experience for parents. In the present systematic literature review, studies on parental posttraumatic symptomatology following birth of a premature infant were reviewed. A total of 5 studies were identified. All studies reviewed found that posttraumatic symptomatology is quite common in parents or primary caregivers of premature infants. However, methodological weaknesses of relevant studies (e.g. use of convenience samples, lack of pre – delivery assessments) make it difficult to draw consistent conclusions regarding prevalence of posttraumatic symptomatology in this population group or whether the experience of a premature birth could be responsible for the development of PTSD. Directions for future research are discussed.

**KEY WORDS:** premature infants, PTSD, post – traumatic symptomatology, literature review.

### **INTRODUCTION**

“Premature” or “preterm” defines infants born <37 weeks of gestation. Prematurity is on the increase in the western countries. In the USA, for example, premature births were 12.1% of all births in 2002 indicating a 29% increase since 1981 (Martin, Hamilton, Sutton, Ventura, et al, 2003). According to the leading charity “Tommy’s,” UK

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Send correspondence to Athanasios Karatzias, PhD

<sup>1</sup>Chartered Psychologist & Lecturer, Napier University, Faculty of Health, Life & Social Sciences, Comely Bank Campus, Crewe Road South, Edinburgh EH4 2LD, Scotland UK, E-mail: t.karatzias@napier.ac.uk Tel: (+44) (0)131 455 5345; Fax: (+44) (0)131 455 5359

<sup>2</sup>Queen Margaret University College, Department of Psychology, UK

<sup>3</sup>Napier University, Faculty of Health, Life & Social Sciences, School of Community Health, UK

<sup>4</sup>The Royal Infirmary of Edinburgh, Simpson Centre for Reproductive Health, UK

<sup>5</sup>University of Stirling, Department of Psychology, UK

has the highest rate of premature birth in Europe with 5 infants born prematurely every hour. In total, more than 45,000 infants are born prematurely in the UK each year and prematurity accounts for 75% of all deaths in the first month of life and 50% of long-term disability (<http://www.tommys.org>). Although from 32 weeks onwards most infants are able to survive with the help of medical technology, 1 in 10 premature infants will develop a permanent disability such as lung disease, cerebral palsy, blindness or deafness. In a UK based study, 62% (n = 314) of premature infants, when they had reached the equivalent of full term (i.e. 40 weeks), presented with one or more of the following conditions, cerebral parenchymal cysts, hydrocephalus, retinopathy of prematurity or continuing need for oxygen treatment (Costeloe, Gibson, Marlow, & Wilkinson, 2000).

The high rates of infant morbidity arising from preterm births impose an immense burden on infants, families and finite health care resources (Campbell & Fleischman, 2001; Petrou, Mehta, Hockley, Cook-Mozaffari, Henderson, & Goldacre, 2003) as well as, social and educational services (Petrou, Sach, & Davidson, 2001). Although the medical and economic sequelae of preterm birth are well documented in the literature, relatively little is known about the parental traumatic aspects of the experience. 'Traumatic' is defined the experience of a threatening situation that goes beyond the bounds of the individual coping strategies and is accompanied by a sense of helplessness and defenseless abandonment (Yehuda, 2002). Post-traumatic stress disorder (PTSD), the clinical manifestation of post-traumatic stress, involves the threat of death or serious injury to the individual or another that is accompanied by intense feelings of fear, helplessness or horror (APA, 2000). PTSD can significantly impair the function and well-being of individuals as it involves re-experiencing the trauma, avoidance of reminders, and persistent increased arousal (Holditch-Davis, Bartlett, Blickman, & Shandor Miles, 2003).

The emotional distress resulting from the experience of having a preterm infant and the subsequent neonatal unit hospitalization may contribute towards post-traumatic stress responses for various reasons, outlined as follows. Having a premature baby may result in parents experiencing a sense of loss of personal control over events, particularly those related to the survival of the infant (Meck, Fowler, Caflin, & Rasmussen, 1995). Parents may also experience a loss of their role as decision makers and care givers of their child (Campbell & Fleischman, 2001) that could be resulted from parent-infant

separation brought about by hospitalisation (Moehn & Rossetti, 1996). It has been suggested that a sense of control is not regained until the infant is discharged from hospital (Affleck, Tennenn, & Rowe, 1991). Previous research has also pointed out that apprehension about the infant's condition underlines the experience of parents (McKim, 1993) and one of the greatest sources of stress for parents may be the appearance of a fragile infant (Raeside, 1997). Studies that focused on the mental state of parents of premature infants have suggested that they present with elevated distress levels including depression and anxiety (Meyer, Coll, Seifer, Ramos, Kilis, & Oh, 1995), although these could be comorbid to post-traumatic symptomatology (e.g. Nixon, Resick, & Nishith, 2004; Zlotnick, Rodriguez, Weisberg, Bruce, Spencer, Culpepper, & Keller, 2004).

#### AIMS OF THE PRESENT REVIEW

There have been thorough reviews on posttraumatic symptomatology following medical illness and treatment (e.g. Tedstone & Tarrier, 2003). However, there has been no review, to our knowledge, on the occurrence of parental posttraumatic symptomatology following the birth of a premature infant. Given the scarcity of evidence in this area, the aims of the present review are first to summarise previous evidence on the occurrence of PTSD symptomatology in parents of premature infants and, secondly, to make suggestions for future research in this area.

#### METHOD

The method followed the guidelines for systematic reviews by Droogan and Cullum (1998), adjusted to the purpose and scope of the present review paper. Studies of quantitative, qualitative, and mixed quantitative-qualitative designs were included, if they fulfilled the following criteria:

- They were published in English
- Participants were parents/carergivers of premature infants
- They were relevant to one or more of the following thematic areas: occurrence of posttraumatic symptomatology following the birth of premature infant, traumatic experiences of parents with premature infants and/or effectiveness of interventions for the

treatment of posttraumatic symptomatology in parents following the birth of a premature infant.

Relevant studies were identified through an electronic search of relevant databases including PsycINFO, Psychology and Behavioral Sciences Collection, Medline, CINAHL, and British Nursing Index. The last update search was in September 2006. Keywords were first entered individually and then were combined. Secondly, each additional search term was entered to each combination. Keywords included Post Traumatic Stress Disorder (PTSD), posttraumatic symptomatology, symptoms, psychopathology, premature infants, babies, children, births, prematurity. Additional keywords included parents, parental, mothers, fathers. It was the original intention of the authors to include both primary research studies and relevant reviews of the literature. However, no relevant reviews or overviews were identified. Only peer-reviewed journals were considered and no attempt was made to identify unpublished studies. The studies included were categorized by methodology and design. Methodological evaluation was based on previously established criteria for evaluating quantitative (Stroup, Berlin, Morton, Olkin, Williamson, et al., 2000) and qualitative studies (Kuckelman-Cobb & Nelson-Hagemaster, 1987; Mays and Pope, 2000) respectively.

## RESULTS

A total of five studies were identified. All five studies included were published after 1997 and were primary research papers. Their main aims, methodology and design varied. The papers were categorized for objectives, method and main results (see Table 1). Findings were synthesized using a narrative summary and presented as follows.

In terms of aims and objectives, two studies had as their primary objective to investigate post-traumatic stress responses of mothers with premature infants (Holditch-Davis, et al., 2003; Kersting, Dorsch, Wesselmann, et al., 2004), one study aimed to investigate the vividness of parents memories in NICU (Wereszczak, Shandor Miles, & Holditch-Davis, 1997), one study aimed to examine the effects of parents' PTSD reactions on sleeping and eating habits of premature children (Pierrhumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003) and one study aimed to test the effectiveness of an intervention for the prevention of PTSD symptomatology in parents with premature children (Jotzo & Poets, 2005).

**Table 1**  
**PTSD following Premature Birth**

<i>Study</i>	<i>Main Objectives</i>	<i>Design</i>	<i>Participants</i>	<i>Interventions</i>	<i>Trauma-related Outcome Measures</i>	<i>Time of Assessment</i>	<i>Results related to PTSD Occurrence</i>
Wereszczak et al (1997)	To study the vividness of memories primary caregivers recall three years after their premature children were born	Qualitative, purposeful cross-sectional	44 primary caregivers including mothers and grandmothers	None	Semi-structured interviews	3 years post-birth	At 3 years post-birth, caregivers reported vivid memories related to the appearance and behaviour of their infant, pain and procedures infants endured, illness severity and uncertainty regarding infant outcomes.
Pierrhumbert et al. (2003)	To examine the effects of PTSD reactions of parents on sleeping and eating problems of premature children	Purposeful, cross-sectional	50 families (mothers and fathers) of premature infants & 25 families of full term infants	None	Perinatal PTSD questionnaire (PPQ) (Quinnell and Hyman, 1999)	18 months post-birth	6% of the control group and 67% of mothers with preterm infants exhibited clinical (DSM-IV) post-traumatic reactions. Intensity of post-traumatic reactions of both parents was an important predictor of sleeping and eating problems of infants.

**Table 1**  
**Continued**

<i>Study</i>	<i>Objectives</i>	<i>Design</i>	<i>Participants</i>	<i>Interventions</i>	<i>Trauma-related Outcome Measures</i>	<i>Time of Assessment</i>	<i>Results</i>
Holditch-Davis et al., (2003)	To investigate post-traumatic stress responses of mothers with premature infants	Descriptive longitudinal, mixed qualitative-quantitative design	30 mothers of high-risk premature infants	None	Semi-structured interview to screen for re-experiencing, avoidance and arousal	During enrolment and when the infant was 6 months old, corrected for prematurity	All mothers interviewed had at least one post-traumatic symptom, 12 had two and 16 had three symptoms. Twenty six mothers reported increased arousal and 24 mothers reported re-experiencing and avoidance. Infant illness severity was significantly associated with post-traumatic symptoms.
Jotzo and Poets (2005)	To test the effectiveness of a trauma-preventive psychological intervention, during hospitalization, for parents of premature infants	Sequential control group design	25 mothers in intervention group & 25 mothers of premature infants in control group	Single session crisis intervention coupled with additional support, throughout hospitalisation when required. It was delivered by psychologist 5 days post-birth	Impact of Events Scale (IES) (Horowitz et al., 1979)	Discharge	19 mothers in the control group showed symptoms of clinical trauma, as measured by IES, post birth, compared to 9 in the intervention group ( $p < .01$ ).

**Table 1**  
**Continued**

<i>Study</i>	<i>Objectives</i>	<i>Design</i>	<i>Participants</i>	<i>Interventions</i>	<i>Trauma-related Outcome Measures</i>	<i>Time of Assessment</i>	<i>Results</i>
Kerling et al., (2004)	To investigate post-traumatic stress responses of mothers with premature infants	Prospective longitudinal	50 mothers of premature infants & 30 mothers after uncomplicated spontaneous birth of a healthy child	None	Impact of Events Scale (IES) (Horowitz et al., 1979)	1–3 days, 14 days, 6 months and 14 months post birth	Mothers of premature infants showed significantly ( $p < .05$ ) higher rates of traumatic symptoms at all time points as measured by IES-total and no reduction in post-traumatic symptomatology (IES-total) 14 months post-birth compared to controls.

In terms of methodology, of the five studies included in this review, three studies were of quantitative methodology (Pierrhumbert, et al., 2003; Kersting et al., 2004; Jotzo & Poets, 2005), one was of qualitative (Wereszczak et al, 1997), and one was of mixed quantitative – qualitative methodology (Holditch-Davis, et al., 2003). With the exception of one study (Jotzo & Poets, 2005) that tested the effectiveness of an intervention for PTSD symptomatology in mothers at risk for premature infants, none of the studies involved an intervention to their designs. All studies samples consisted of mothers, one included fathers as well (Pierrhumbert et al., 2003), and another other female primary caregivers (Wereszczak et al, 1997). Sample size ranged between 25 and 50 participants per group across studies. Two studies (Jotzo & Poets, 2005; Kersting et al., 2004) employed Impact of Event Scale (IES) (Horowitz, Wilner, & Alvarez, 1979), two studies employed semi-structured interviews (Wereszczak et al, 1997; Holditch-Davis et al., 2003) and one study (Pierrhumbert et al., 2003) employed the Perinatal PTSD Questionnaire (PPQ) (Quinnell and Hynan, 1999) for the assessment of posttraumatic symptomatology in parents with premature infants. Two of the studies were longitudinal and assessed PTSD symptomatology at least two times post-birth; 6 months in one study (Holditch-Davis et al., 2003) and 14 months in the second study (Kersting et al., 2004). The remaining three studies (Wereszczak et al, 1997; Pierrhumbert et al., 2003; Jotzo & Poets, 2005) were cross sectional. In these studies time of assessment of PTSD symptomatology varied from discharge to 3 years post birth.

All studies reviewed found that posttraumatic symptomatology is quite common in parents or primary caregivers of premature infants. In one study 67% of mothers with preterm infants vs. 6% of the control group exhibited clinical PTSD reactions (Pierrhumbert et al., 2003) post birth. Holditch-Davis et al. (2003) found that all mothers interviewed had at least one posttraumatic symptom, 12 had two, and 16 had three symptoms, post birth. A total of 26 mothers reported increased arousal and 24 mothers reported re-experiencing and avoidance (n = 30). Kersting et al. (2004) found that mothers of premature infants (n = 50) showed significantly ( $p < .05$ ) higher rates of traumatic symptoms at all time points (1–3 days, 14 days, 6 months and 14 months) post birth as measured by IES-total and no reduction in posttraumatic symptomatology (IES-total), 14 months post-birth compared to controls (n = 50). Wereszczak et al. (1997) also found that at 3 years post-birth, caregivers (n = 44) reported vivid memories



related to the appearance and behaviour of their infant, pain and procedures infants endured, illness severity and uncertainty regarding infant outcomes. Finally, Jotzo and Poets (2005) have shown that a preventive crisis intervention could significantly minimise the risk for PTSD morbidity in mothers with premature infants ( $n = 25$ ) compared to controls ( $n = 25$ ).

## DISCUSSION

It could be concluded from the present review that posttraumatic symptomatology is common in parents and other primary caregivers of premature infants and such symptomatology is likely to be long term. However, there is a distinctive lack of relevant research in the area. Furthermore, research on the perspectives of parents of premature infants is limited and the evidence provided fragmented and sporadic. This is because parental accounts have been rarely included along with standardised questionnaires. There is also a distinctive lack of intervention studies in this particular group. Therefore, information on effective strategies for addressing posttraumatic reaction and symptomatology, in parents with pre term infants is rather limited.

A number of methodological limitations have also compromised the quality of information provided by the limited number of studies. Studies on parental post-traumatic symptomatology appear to be rather diverse regarding sample characteristics, time of assessment, and research design. They are also characterised by convenience samples of small size. In addition, previous relevant studies tend to focus mainly, if not exclusively, on mothers and rarely included fathers in the sample. This is despite previous findings that fathers are the primary source of support for mothers during the postpartum period making them equally if not more prone to psychological distress (Crockenberg, 1987). Furthermore, previous relevant studies did not control for illness severity of the infant and pre birth posttraumatic symptomatology. Finally, none of the studies reviewed used a clinician administered assessment tool for the assessment of post-traumatic symptomatology such as the Clinician-Administered PTSD Scale (CAPS) (Blake, Weathers, Nagy, Kaloupek, Klauminzer, Charney, & Keane, 1990) or included pre birth assessment of parental PTSD symptomatology in their design. Therefore, we are unable to define the morbidity of posttraumatic symptomatology in this population group or whether the experience of premature birth alone could be responsible for the development of PTSD.

Considering the findings of the present review, future research in the area should consider the following: Assessing posttraumatic symptomatology by means of standardized clinical scales alongside open-ended interview schedules in order to obtain the views of parents, pre- and post-birth. Long-term follow up assessments could also offer valuable information regarding the natural history of posttraumatic symptomatology in this group. Fathers as well as mothers should be included in the sample, whenever possible and data on infant factors (i.e., infant illness severity index should be recorded). The above considerations would increase rigour in research on posttraumatic symptoms of parents of premature infants and may result in valuable epidemiological data about the prevalence of such symptomatology shortly after birth and in the long-term. Such research would also lead to a better understanding of the aspects surrounding a premature birth that might trigger a posttraumatic response and finally a better understanding of parental difficulties and needs. Such an understanding could have direct implications for the provision of evidence based family focused care, more effective use of resources and reduction in distress for parents as well as health professionals.

Furthermore, pre-term births have been associated with high maternal depression scores (Drewett, Blair, Emmett, & Emond, 2004). Common trends in memory function and information processing in patients with PTSD and depression have also been found. It has been suggested, for example, that there is a bias enhanced recall of trauma related material and in the retrieval of autobiographical memories of certain incidents in both population groups (Buckley, Blanchard, & Neal, 2000).

Trauma victims with PTSD also tend to have increased negative beliefs about the self, others and the world compared to trauma victims without PTSD (Foa, Ehlers, Clark, Tollin, & Orsillo, 1999). Such beliefs are also very common in patients with depression (Beck, Rush, Shaw, & Emery, 1979). Considering the above it would be of interest to explore further the association between depression and PTSD in this population group.

## REFERENCES

- Affleck, G., Tennenn, H., & Rowe, J. (1991). *Infants in crisis: How parents cope with newborn intensive care and its aftermath*. New York: Springer-Verlag.

- Allen, E.C., Manuel, J.C., Legault, C., Naughton, M.J., Pivor, C., & O'Shea, T.M. (2004). Perception of child vulnerability among mothers of former premature infants. *Pediatrics, 113*, 267–73.
- American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders*. Washington DC: American Psychiatric Association.
- Beck, A.T., Rush, A.J., Shaw, B.F., & Emery, G. (1979). *Cognitive therapy for depression*. New York: Guilford.
- Blake, D., Weathers, F., Nagy, L., Kaloupek, D., Klauminzer, G., Charney, D., & Keane T (1990). *Clinician Administered PTSD Scale (CAPS)*. Boston: National Center for Post-traumatic Stress Disorder.
- Buckley, T.C., Blanchard, E.B., & Neil, W.T. (2000). Information processing and PTSD: A review of the empirical literature. *Clinical Psychology Review, 20*, 1041–1065.
- Campbell, D.E. & Fleischman, A.R. (2001). Limits of viability: Dilemmas, decisions, and decision makers. *American Journal of Perinatology, 18*, 117–128.
- Costeloe, K., Gibson, A.T., Marlow, N., & Wilkinson, A.R. (2000). The EPICure Study: Outcome to discharge from hospital for infants born at the threshold of viability. *Pediatrics, 106*, 659–671.
- Crockenburg, S. (1987). Support for adolescent mothers during the postnatal period: Theory and research. In C.F.Z. Boukydis (Ed.), *Research on support for parents and infants in the postnatal period*. Norwood, NJ: Abdex.
- Drewett, R., Blair, P., Emmett, P., & Emond, A. (2004). Failure to thrive in the term and preterm infants of mothers depressed in the postnatal period: A population-based birth control study. *Journal of Child Psychology and Psychiatry, 45*, 359–366.
- Droogan, J. & Cullum, N. (1998). Systematic reviews in nursing. *International Journal of Nursing Studies, 35*, 13–22.
- Foa, E.B., Ehlers, A., Clark, D.M., Tolin, D.F., & Orsillo, S.M. (1999). The Posttraumatic Cognitions Inventory (PTCI): Development and validation. *Psychological Assessment, 11*, 303–314.
- Holditch-Davis, D., Bartlett, T.R., Blickman, A.L., & Shandor Miles, M. (2003). Posttraumatic stress symptoms in mothers of premature infants. *JOGNN, 32*, 161–171.
- Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine, 41*, 209–218.
- Jotzo, M. & Poets, C.F. (2005). Helping parents cope with the trauma of premature birth: An evaluation of a trauma-preventive psychological intervention. *Pediatrics, 115*, 915–919.
- Kersting, A., Dorsch, M., Wesselmann, U., et al. (2004). Maternal posttraumatic stress response after the birth of a very low-birth-weight infant. *Journal of Psychosomatic Research, 57*, 473–476.
- Kuckelman Cobb, A. & Nelson Hagemaster, J. (1987). Ten criteria for evaluating qualitative research proposals. *Journal of Nursing Education, 26*, 138–142.
- Martin, J.A., Hamilton, B.E., Sutton, P.D., Ventura, S.J., et al. (2003). *Births: Final data for 2002*. National Vital Statistics Reports, 52. Hyattsville, MD: National Centre for Health Statistics.
- Mays, N. & Pope, C. (2000). Qualitative Research in Health Care: Assessing Quality in Qualitative Research. *British Medical Journal, 320*, 50–52.
- McKim, E.M. (1993). The information and support needs of mothers of premature infants. *Journal of Pediatric Nursing, 8*, 233–244.
- Meck, N.E., Fowler, S.A., Clafin, K., & Rasmussen, L.B. (1995). Mothers' perceptions of their NICU experience 1 and 7 months after discharge. *Journal of Early Intervention, 19*, 288–301.
- Meyer, E.C., Coll, C.T.G., Seifer, R., Ramos, A., Kilis, E., & Oh, W. (1995). Psychological distress in mothers of preterm infants. *Developmental and Behavioural Pediatrics, 16*, 412–417.

- Moehn, D.G. & Rossetti, L. (1996). The effects of neonatal intensive care on parental emotions and attachment. *Infant-Toddler Intervention: The Transdisciplinary Journal*, 6, 229–246.
- Nixon, R.D.V., Resick, P.A., & Nishith, P. (2004). An exploration of comorbid depression among female victims of intimate partner violence with posttraumatic stress disorder. *Journal of Affective Disorders*, 82, 315–320.
- Petrou, S., Mehta, Z., Hockley, C., Cook-Mozaffari, P., Henderson, J., & Goldacre, M. (2003). The impact of a preterm baby on hospital inpatient admissions and costs during the first 5 years of life. *Pediatrics*, 112, 1290–1297.
- Petrou, S., Sach, T., & Davidson, L. (2001). The long-term costs of preterm babies and low birth weight: results of a systematic review. *Child: Health Care and Development*, 27, 97–115.
- Pierrhumbert, B., Nicole, A., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2005). Parental post-traumatic reactions after premature birth: Implications for sleeping and eating problems in the infant. *Archives of Disease in Childhood and Fetal and Neonatal Education*, 88, 400–404.
- Quinnell, F.A. & Hynan, M.T. (1999). Convergent and discriminant validity of the Perinatal PTSD Questionnaire (PPQ): A preliminary study. *Journal of Traumatic Stress*, 12, 193–199.
- Raeside, L. (1997). Perceptions of environmental stressors in the neonatal unit. *British Journal of Nursing*, 6, 914–923.
- Stroup, D.F., Berlin, J.A., Morton, S.C., Olkin, I., Williamson, G.D., Rennie, D., Moher, D., Becker, B.J., Sipe, T.A., & Thacker, S.B. (2000). Meta-analysis of observational studies in epidemiology. *Journal of the American Medical Association*, 283, 2008–2012.
- Tedstone, J.E. & TARRIER, N. (2003). Posttraumatic stress disorder following medical illness and treatment. *Clinical Psychology Review*, 23, 409–448.
- Tommys Charity (), Available at <http://www.tommys.org>. Accessed July 2005.
- Wereszczak, J., Shandor Miles, M., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit. *Neonatal Network*, 16, 33–40.
- Yehuda, R. (2002). Clinical relevance of biologic findings in PTSD. *Psychiatric Quarterly*, 73, 23–33.
- Zlotnick, C., Rodriguez, B.F., Weisberg, R.B., Bruce, S.E., Spencer, M.A., Culpepper, L., & Keller, M.B. (2004). Chronicity in posttraumatic stress disorder and predictors of the course of posttraumatic stress disorder among primary care patients. *Journal of Nervous and Mental Disease*, 192, 153–159.