Long-Term Maternal Stress and Post-traumatic Stress Symptoms Related to Developmental Outcome of Extremely Premature Infants

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Abstract
In this study, we examined the relations between the severity of developmental outcomes of extremely low birth weight (ELBW) children and their mothers’ stress and post-traumatic stress disorder (PTSD) symptoms, 4–16 years after birth. Israeli mothers (N = 78) of a cohort of extremely premature infants (24–27 weeks) born 4–16 years earlier were asked to report about the medical and developmental condition of their child and their current perceived stress and PTSD symptoms. Results show that mothers of ELBW children with normal development reported the lowest perceived stress compared with mothers of ELBW children with developmental difficulties. We also found that 25.6% of the mothers had the potential to suffer from PTSD following the birth of an ELBW child. Furthermore, the severity of prematurity developmental outcomes made a significant contribution to mothers’ perceived stress. To sum, mothers of ELBW infants’ perceived stress is related to their children’s severity of prematurity developmental outcomes, 4–16 years after birth. Clinical implications of these findings are discussed. Copyright © 2013 John Wiley & Sons, Ltd.

Keywords
post-traumatic stress disorder (PTSD) symptoms; extremely low birth weight (ELBW); stress; neonatal intensive care unit (NICU)

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Introduction
In recent years, in the wake of technological and medical improvements, there has been an increase in the rate of pre-term infants born at 24–27 weeks with extremely low birth weight (ELBW; <1 kg) who have survived (Claas et al., 2011). However, this population is known to suffer from significantly higher rates of developmental disabilities and chronic disorders (Iacovidou, Varsami, & Syggellou, 2010).

The birth of a premature infant and the subsequent hospitalization in a neonatal intensive care unit (NICU) are known as potentially stressful experiences that might affect the newborn’s close relatives. The literature indicates a link between early gestational week and the low chances of survival and more developmental disabilities as a result of the prematurity (e.g. Bart, Shayevits, Gabis, & Morag, 2011). Studies have shown that premature infants’ mothers are at high risk for significant psychological distress compared with mothers of term infants (Trombini, Surcinelli, Piccioni, Alessandroni, & Faldella, 2008) Apart from the birth of a premature infant, most mothers of ELBW children need to face parenting of a sick and disabled child that might increase their parental stress. Indeed, a recent meta-analysis study concludes that in general parents of pre-term-born children experience slightly more stress than parents of term-born children (Schappin, Wijnroks, Uniken Venema, & Jongmans, 2013).

Looking beyond parental experiences in the first year after birth, results of studies are mixed. In a recent meta-analysis study, it was found that in general, the parental stress levels on two of the three stress scales decrease with child age (i.e. child’s distractibility and parents’ health). However, on one scale, parental stress increased with child age (i.e. child’s acceptability) (Schappin et al., 2013). More specifically, it was found that 2 years after birth, mothers of very low birth weight (VLBW) infants with high risk for prematurity complications reported higher levels of stress than mothers of low-risk VLBW infants or mothers of term children. Furthermore, infants’ high medical risk, maternal low levels of social support and ways of coping independently...
predicted mothers’ general psychological distress (Eisengart, Singer, Fulton, & Baley, 2003). In other studies, at 2 (Tommisika, Östberg, & Fellman, 2002) and 3 (Singer et al., 1999) years after birth, mothers of high-risk VLBW children did not differ from mothers of term children in general psychological distress but only in parental stress.

A number of studies indicated that parental stress might continue into the childhood and adolescent periods of a premature infant. For example, one study found that mothers of VLBW children aged 5 years suffered from higher levels of general psychological distress and lower quality of life compared with mothers of children with normal birth weight (Witt et al., 2012). In another study, mothers of high-risk VLBW children aged 8 years reported greater family and social impact, greater personal strain and greater financial strain compared with the mothers of term children, specifically if their school-aged children had lower IQ scores and higher rates of mental retardation (Singer et al., 2007). The groups did not differ in their general psychological distress. Multiple births, low socio-economic status and lower child IQ contributed to maternal stress (Singer et al., 2007).

During late childhood, among children aged 11 years and born weighing less than 750 g, parents were found to report a sense of low parental competence, attachment difficulties with the child and concerns about his or her future (Taylor, Klein, Minich, & Hack, 2000). Entering early adolescence, parents of ELBW aged 12–16 years reported that their child’s health affected their emotional health (Saigal, Burrows, Stoskopf, Rosenbaum, & Steiner, 2000). In another longitudinal study (Singer et al., 2010), mothers of high-risk VLBW children reported greater overall child-related stress than mothers of term children. However, at the age of 14 years, mothers of high-risk VLBW children and mothers of term children did not differ in their child-related stress, whereas mothers of low-risk VLBW reported the lowest levels of stress compared with the two other groups. As can be seen from this review, the parental stress among mothers of ELBW children at school age has scarcely been studied. It is important to investigate this issue as the mutual effects between the developmental conditions of ELBW children and mothers perceived stress continue years after birth.

In recent years there is a body of knowledge suggesting that the birth and parenting to an ELBW infant might also be experienced as traumatic, even without actual threat to the life of the mother or infant (e.g. Karatzias, Chouliara, Maxton, Freer, & Power, 2007). Several studies have pointed to the possibility that mothers of premature infants, especially VLBW infants, might suffer from stress-related psychopathology, and specifically from post-traumatic stress disorder (PTSD; Feeley et al., 2011).

According to the DSM-IV-TR (American Psychiatric Association, 2000), individuals diagnosed with PTSD need to meet the criteria for three clusters of symptoms: (a) intrusion: re-experience of the trauma (e.g. flashbacks); (b) avoidance of trauma reminders and general emotional numbing; and (c) hyperarousal: persistent increased arousal (e.g. irritability). Symptoms of PTSD usually occur within 3 months of a traumatic event and commonly follow a chronic course.

Studies have shown that mothers may develop PTSD symptoms as a reaction to the stay in the NICU following the birth of a premature infant (Feeley et al., 2011). It was also found that there is a positive association between mothers’ PTSD symptoms and their difficulties in bonding with their child (Feeley et al., 2011). Furthermore, the more severe the condition experienced by the pre-term newborn in the NICU, the higher the probability his mother will experience PTSD symptoms, 6 months after birth (Feeley et al., 2011).

The literature shows that PTSD symptoms among mothers of VLBW infants continue to appear 2–3 years after birth. Ahlund, Clarke, and Hill (2009) claimed that the duration of stay in the NICU and the lack of social support received by the mother are important factors that may explain why they continue to suffer from PTSD symptoms for several years after birth. Elkli, Hartvig, and Christiansen (2007) found that among ELBW infants 3 years after birth, 20% of the mothers met the diagnosis of PTSD and another 10% reported sub-clinical PTSD. The most influential factors that explained mothers’ PTSD symptoms were children’s degree of disability, poor contact with the NICU staff and general distress of the mother during their stay in the NICU. To the best of our knowledge, there are no studies that examined potential for PTSD symptoms among mothers of ELBW children more than 3 years after birth.

To summarize, most studies followed mothers of VLBW children over the first years after birth (e.g. Eisengart et al., 2003). There are only a few studies that examined the long-term outcomes of VLBW children with reference to mothers’ perceived stress for a longer period after the birth (e.g. Singer et al., 2010). Furthermore, there are no studies that examined PTSD symptoms among mothers of ELBW children years after the birth. The current study aims to fill this gap by the examination of perceived stress and PTSD symptoms among a sample of ELBW children’s mothers, 4–16 years after birth, when most children are in the important developmental phase of late childhood. Furthermore, as ELBW children are liable to suffer from developmental disabilities, and children’s behavioral and cognitive outcomes are known to be related to maternal psychological status (Raina et al., 2005), this study aims to examine the relations between ELBW severity of prematurity, developmental outcomes and mothers of ELBW children perceived stress and PTSD symptoms. Such symptoms, if present, are important for medical decision-making and the design of intervention programs to improve mothers’ and ELBW children’s outcomes.
We hypothesize that 4–16 years after birth: (1) mothers of ELBW children with developmental difficulties will report higher levels of perceived stress and (2) more PTSD symptoms as compared with mothers of ELBW children with normal development; (3) in an integrative model, the severity of prematurity developmental outcomes will predict mothers’ perceived stress and (4) PTSD symptoms, above and beyond the contribution of sociodemographic and negative life events after birth variables.

Methods

Participants

The study sample includes Israeli mothers of 78 ELBW infants that responded to questionnaires regarding their emotional condition. These participants are part of the mothers of 97 ELBW infants who responded to the preliminary telephone questionnaire regarding the developmental characteristics of their children. The ELBW infants were born at a single hospital (Tel Hashomer) from 1995 to 2006 and were admitted at the centre’s NICU (mean birth year was 2001; Reichman, Levitski, Boyko, & Lerner-Geva, 2009). We note that we have no information as to the length of stay in the NICU. However, according to hospital policies, the minimal stay for 24–27 weeks prematurity was 9 weeks. Table I shows the demographic characteristics of the children and the mothers.

The original list of participants originated from the perinatal national database of premature infants and included a cohort of 134 ELBW infants. Fifty-six mothers of ELBW infants did not participate in this study (41.7%). Mothers of 14 ELBW infants could not be reached for various reasons (10.4%). Two ELBW infants were deceased and were therefore excluded (1.4%). Mothers of 21 ELBW infants refused to respond to the telephone questionnaire regarding the developmental characteristics of their children in the study (15.6%). Finally, mothers of 19 ELBW infants did not respond to questionnaires regarding their emotional condition (14.1%).

To examine whether research results are biased because of the differences between mothers of ELBW children who participate in the study (n = 78) compared with mothers of ELBW children who did not participate (n = 56), we conducted a number of t-test and chi-square analyses. We did not find significant differences between the groups with regard to premature infant’s birth weight, birth week and, child’s current age, child’s gender and the number of pregnancies with multiple gestations.

Procedure

The study began by gathering relevant medical data from the children’s records in terms of pre-natal, birth characteristics, developmental disorders, demographic and family characteristics. Subsequently, a written and phone consents were requested. The protocol and phone consents were approved by the local Helsinki committee. Participation in the study was voluntary pending consent. Mothers who agreed to participate were asked to answer a short telephone questionnaire regarding the medical and developmental condition of their children and were requested to agree to filling out a set of questionnaires regarding their own emotional condition, which would be mailed to them. We allowed the mothers to choose the most convenient way for filling in the questionnaires.

Measures

Telephone questionnaire for mothers of extremely low birth weight children

This questionnaire was constructed for the purposes of the present study to monitor the medical and developmental condition of the ELBW children. The questionnaire consists of 27 items. The questionnaire covers the following topics: family background, birth experience, medical condition and development of the pre-term child, the child’s current educational setting, types of treatments the child received and demographic questions. The questionnaire was based on follow-up studies that examined the developmental consequences of prematurity of VLBW and ELBW children (Mercier, Dunn, Ferrelli, Howard, & Soll, 2010).

Perinatal Post-Traumatic Stress Disorder Questionnaire—modified (Callahan, Borja, & Hynan, 2006)

This self-report questionnaire is an adaptation of the Perinatal Post-Traumatic Stress Disorder Questionnaire (DeMier, Hynan, Harris, & Manniello, 1996). It was designed to examine post-traumatic stress symptoms following birth experiences. The questionnaire was translated into Hebrew by the study authors using the back-translation method. The questionnaire consists of 14 questions covering the three PTSD symptoms clusters: re-experiencing, avoidance and hyper-arousal. Respondents are ask to indicate how frequently she has experienced each reaction during the last 6 months on a five-point scale ranging from ‘never’ (0) to ‘often, for more than a month’ (4). We used the sum of scores as an index of PTSD symptoms. In addition, as suggested by Callahan et al. (2006), we calculated a cut-off score of 19 points indicating the potential for self-reported PTSD. Previous studies reported a good discriminant and convergent validity, high internal (α = 0.90) and test-retest reliabilities (α = 0.92) of the questionnaire (Callahan et al., 2006). The present study found high internal reliability (α = 0.91).

Parental Stress Index—Short Form (Abidin, 1995)

This self-report questionnaire was designed to examine parental stress with respect to child and parent characteristics. The questionnaire consists of 36 items...
and is comprised of three sub-scales: parent distress, dysfunctional interaction and difficult child. Participants are asked to mark their answers on a five-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). The index score is the average of each sub-scale, and the total score is the average of the three sub-scales. Previous studies reported high internal (α = 0.91) and test-retest reliabilities (α = 0.84) for the questionnaire. The present study found high internal reliability for the Parental Stress Index—Short Form total score (α = 0.94) and the three sub-scales: parental distress (α = 0.93), dysfunctional interaction (α = 0.79) and difficult child (α = 0.87).

Life Events Questionnaire (Solomon & Flum, 1988)
Life Events Questionnaire comprised of 23 life events tapping four domains: family (e.g. divorce), work (e.g. dismissal), health (e.g. major disease) and personal events (e.g. accident). Participants were asked whether they had experienced any of the events since the ELBW child birth and to indicate whether the experienced events were perceived by them as positive or negative. The sum of negative life events after the birth was used for analysis.

Data analyses
Firstly, we constructed a new variable called ‘severity of prematurity developmental outcomes’, which unites all the long-term extreme prematurity consequences. The variable was constructed based on the combination of methods that were introduced in previous studies among this population (e.g. Steinmacher et al., 2008), nevertheless it is still exploratory. The variable consists of three levels: (1) severe developmental difficulties—children who need constant and continuous care or who suffer from severe disorders such as cerebral palsy, mental retardation, autism, visual or hearing impairments. Also, children who regularly use a gastrostomy or tracheostomy were included; (2) mild to moderate developmental difficulties—any deviation from normal development or less severe prematurity complications that do not require constant care. The following difficulties were included: motor difficulties, learning disabilities, attention deficit and hyperactivity disorder or other developmental diagnosis. Also included were

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child characteristics (n = 78)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gestational age (weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth weight (g)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ELBW (&lt;1 Kg)</td>
<td>75 (96.2)</td>
<td>752.67 (66.59)</td>
</tr>
<tr>
<td>VLBW (&lt;1.5 Kg)</td>
<td>3 (3.8)</td>
<td>1095.66 (110.21)</td>
</tr>
<tr>
<td>Age at the time of study</td>
<td>101 (93.5)</td>
<td>10.17 (3.43)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46 (59)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>32 (41)</td>
<td></td>
</tr>
<tr>
<td>Multiple gestations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>45 (57.7)</td>
<td></td>
</tr>
<tr>
<td>Twins</td>
<td>30 (38.5)</td>
<td></td>
</tr>
<tr>
<td>Triplet</td>
<td>3 (3.8)</td>
<td></td>
</tr>
<tr>
<td>Maternal characteristics (n = 78)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at study*</td>
<td>64 (81)</td>
<td>39.33 (6.73)</td>
</tr>
<tr>
<td>Age at child birth*</td>
<td></td>
<td>29.89 (5.76)</td>
</tr>
<tr>
<td>Place of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>64 (81)</td>
<td></td>
</tr>
<tr>
<td>Former Soviet republics</td>
<td>8 (10.1)</td>
<td></td>
</tr>
<tr>
<td>Asia/Africa</td>
<td>3 (3.8)</td>
<td></td>
</tr>
<tr>
<td>Europe, America, Australia</td>
<td>4 (5.1)</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married to premature infant’s father</td>
<td>65 (82.5)</td>
<td></td>
</tr>
<tr>
<td>Divorced from premature infant’s father</td>
<td>8 (10.1)</td>
<td></td>
</tr>
<tr>
<td>Single parent</td>
<td>6 (7.6)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>1 (1.3)</td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>19 (24.1)</td>
<td></td>
</tr>
<tr>
<td>College or voc/tech program</td>
<td>17 (21.5)</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>42 (53.2)</td>
<td></td>
</tr>
<tr>
<td>Income†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Above average</td>
<td>27 (34.6)</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>25 (29.5)</td>
<td></td>
</tr>
<tr>
<td>Below average</td>
<td>28 (35.9)</td>
<td></td>
</tr>
</tbody>
</table>

ELBW: extremely low birth weight; VLBW: very low birth weight.
*In years.
†Average income for family was defined as 13,000 NIS.
epilepsy, a slight hearing decrease, respiratory problems, digestive, heart or blood problems, receiving growth hormone, frequent hospitalizations in recent years, taking medication regularly and hydrocephalus (which is not accompanied by additional brain injury); and (3) normal development—children without developmental difficulties or any other prematurity complications who attend a regular school day without an assistant.

Secondly, we performed statistical comparisons between mothers’ perceived stress and PTSD symptoms according to the severity of prematurity developmental outcomes using analysis of variance (ANOVA). In addition, we tested the contributions of sociodemographic variables, negative life events after birth and the severity of prematurity developmental outcome to the emotional state of mothers through a series of hierarchical regressions. All analyses were conducted using SPSS software version 19 (IBM Corporation, New Orchard Road 1 Armonk, New York, USA).

**Results**

**Mothers’ distress according to severity of prematurity developmental outcomes**

As a preliminary analysis, we assessed the prevalence of severity of prematurity developmental difficulties of ELBW children, 4–16 years after birth. We found that according to mothers reports, 29.8% (n = 31) of the infants were developed normally, 31.7% (n = 33) had mild to moderate developmental difficulties, and 38.5% (n = 40) had severe developmental difficulties. In addition, we have examined differences between the three groups regarding children’s background characteristics. Our results show that the three groups did not differ in children age (F(2, 77) = 1.35, p = 0.26), gestational age (F(2, 77) = 0.84, p = 0.43), birth weight (F(2, 77) = 2.80, p < 0.07) and gender distribution (χ²(2) = 4.83, p = 0.09).

The study’s first hypothesis was that mothers of ELBW children with developmental difficulties will report higher levels of perceived stress compared with mothers of ELBW children with normal development, 4–16 years after birth. We performed an ANOVA with Scheffe post-hoc tests for general perceived stress. As can be seen in Table II, we found significant differences between the groups, F(2, 74) = 7.41, p < 0.05, η² = 0.17. Mothers of ELBW children with normal development reported the lowest perceived stress compared to mothers of ELBW children with mild to moderate difficulties and mothers of ELBW children with severe developmental difficulties. Mothers of ELBW children with mild to moderate difficulties did not differ in their levels of perceived stress from mothers of ELBW children with severe developmental difficulties. In addition, we examined parental perceived stress on three Perinatal Post-Traumatic Stress Disorder Questionnaire—modified (PPQ-II) subscales. As can be seen in Table II and according to our hypothesis, we found significant differences in all three indexes of ‘parental distress’ F(2, 74) = 5.42, p < 0.05, η² = 0.13; ‘dysfunctional interaction’ F(2, 74) = 3.42, p < 0.05, η² = 0.08 and ‘difficult child’ F(2, 74) = 8.26, p < 0.05, η² = 0.18. Scheffe post-hoc tests indicate that mothers of ELBW children with normal development reported the lowest levels of parental distress and difficult child indexes compared to mothers of ELBW children with mild to moderate difficulties and mothers of ELBW children with severe developmental difficulties. Mothers of ELBW children with mild to moderate difficulties did not differ in their levels of parental distress and difficult child indexes from mothers of ELBW children with severe developmental difficulties. Furthermore, mothers of ELBW children with normal development reported the lowest levels of dysfunctional interaction compared to mothers of ELBW children with severe developmental difficulties. Mothers of ELBW children with mild to moderate difficulties did not differ in their levels of dysfunctional interaction index from mothers of ELBW children with severe developmental difficulties. It is worth noting that there was no main age effect on parental distress (F(3, 77) = 0.59, p = 0.61), neither did age interact with the severity of the developmental outcome (F(6, 77) = 0.79, p = 0.58).

The study’s second hypothesis was that mothers of ELBW children with developmental difficulties would

**Table II.** Means (M) and standard deviation (SD) for perceived stress and post-traumatic stress disorder symptoms according to severity of prematurity outcomes

<table>
<thead>
<tr>
<th>Severity of prematurity outcomes</th>
<th>Normal development</th>
<th>Mild to moderate developmental difficulties</th>
<th>Severe developmental difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>General perceived stress (PSI-SF)</td>
<td>1.69a</td>
<td>0.46</td>
<td>2.26b</td>
</tr>
<tr>
<td>Parental distress</td>
<td>1.69a</td>
<td>0.61</td>
<td>2.42b</td>
</tr>
<tr>
<td>Dysfunctional interaction</td>
<td>1.73a</td>
<td>0.55</td>
<td>2.04</td>
</tr>
<tr>
<td>Difficult child</td>
<td>1.65a</td>
<td>0.46</td>
<td>2.32b</td>
</tr>
<tr>
<td>Post-traumatic symptoms (PPQ-II)</td>
<td>10.25</td>
<td>0.60</td>
<td>13.65</td>
</tr>
</tbody>
</table>

M: mean; SD: standard deviation; PSI-SF: Parental Stress Index—Short Form; PPQ-II: Perinatal Post-Traumatic Stress Disorder Questionnaire—modified. Means with different lettering differ in their significance levels (*p < 0.05) in post-hoc Scheffe test.
report higher levels of PTSD symptoms, compared with mothers of ELBW children with normal development, 4–16 years after birth. To test this hypothesis, we performed an ANOVA with ‘Scheffe’ post-hoc tests for the PTSD symptoms according to the PPQ-II (Callahan et al., 2006). As can be seen in Table II, we did not find significant differences between the groups, $F(2, 75) = 1.80, p = 0.17$, although the trend of results was in the direction of our hypothesis. As mentioned, the potential for self-report-based PTSD is determined according to a threshold score of 19 points or more in the PPQ-II. We found that 25.6% of the mothers in the study had the potential to suffer from PTSD following the birth of an ELBW child. We did not find significant differences between the groups in the potential for self-report-based PTSD [normal development = 12.5% ($n = 3$); mild to moderate difficulties = 24.1% ($n = 7$) and severe difficulties = 40% ($n = 10$; $\chi^2(2) = 4.91$, $p = 0.09$)].

It is worth noting that there was no main age effect on PTSD symptoms ($F(3, 77) = 0.89$, $p = 0.44$), nor did age interact with the severity of the developmental outcome ($F(6, 77) = 0.88$, $p = 0.51$).

**Predicting mothers’ perceived stress and post-traumatic symptoms by sociodemographic variables, negative life event after birth and severity of prematurity developmental outcomes**

Our third hypothesis was that severity of prematurity developmental outcomes would contribute to mothers’ perceived stress above and beyond the contributions of sociodemographic variables and negative life events after birth variables. To test this, two three-step hierarchical regression analyses were conducted. In the first step of each regression, we entered six sociodemographic variables as control variables. These variables are known to be related to mothers’ distress following the birth of a premature infant. The variables were age, marital status, number of siblings, siblings with developmental disorders, mothers’ education and family income. In the second step, we entered the number of mothers’ negative life events after birth variable. In the third step, we entered the severity of prematurity developmental outcomes. Nominal variables (marital status, siblings with disorders, education, income level and severity of prematurity outcomes) were entered into the regression as dummy variable. All other variables were standardized before entrance into the regression. Table III presents regression coefficients for the prediction of mothers’ stress and PTSD symptoms.

The total set of variables explained 52.7% of the mothers’ general perceived stress variance ($F(10, 75) = 7.25$, $p < 0.05$). As can be seen in Table III, in the final model, we found that among the sociodemographic variables, the level of education was negatively associated with mothers’ perceived stress. The less educated the mother, the higher levels of stress she reported. Furthermore, we found that the negative life events variable had a significant positive contribution to mothers’ perceived stress. In other words, the more negative life events after birth mothers reported, the higher her levels of perceived stress. Last, we found that above and beyond the contribution of the other variables, the severity of prematurity developmental outcomes made a significant negative contribution to mothers’ perceived stress. Mothers of developmentally delayed children (irrespective of the severity of this delay) reported more stress than mothers of normally developed children. Our fourth hypothesis was that severity of prematurity developmental outcomes would contribute to mothers’ PTSD symptoms, above and beyond the contributions of sociodemographic variables and negative life events after birth. As for the PTSD symptoms, the total set of variables explained 51.4% of the variance ($F(10, 75) = 6.97$, $p < 0.05$). As can be seen in Table III, in the final model, we found that among the sociodemographic variables, the number of infants’ siblings variable was positively associated with mothers’ PTSD symptoms. The more siblings the infant had, the higher levels of PTSD symptoms his mother reported. Furthermore, we found that the negative life events variable made a significant positive contribution to mothers’ PTSD symptoms. In other words, the more negative life events after birth mothers reported, the higher the levels of PTSD symptoms they experienced.

None of the other variables were found to significantly contribute to mothers’ PTSD symptoms variance.

**Discussion**

The present study aimed to examine the relations between ELBW severity of prematurity developmental outcomes and stress and PTSD symptoms, 4–16 years after birth. As hypothesized, we found that mothers of ELBW children suffer from higher perceived stress than mothers of ELBW children with normal developing children, 4–16 years after birth. This finding is consistent with literature indicating a link between the severity of prematurity developmental outcomes and mothers’ emotional state in the period of late childhood (Singer et al., 2007; Taylor et al., 2000). Although most studies focused on the first years after birth (Eisengart et al., 2003), our study is one of the first to examine a long-term period after birth when most of the ELBW children are in their school years and their mothers are in their 40s.

The conservation of resources theory (COR; Hobfoll, 2001) can be used to explain these findings. The COR theory integrates both environmental and psychological factors in order to shed light on the process of stress formation. The theory’s basic assumption is that people strive to achieve, maintain, protect and nurture things they perceive as valuable; all are conceptualized as their resources. Following this assumption, experience of stress is a result of loss of resources (e.g.
loss of a family member), threat to existing resources (e.g. acute illness) or investment in unrewarding resources (e.g. loss of income after financial investment). The experience of stress among mothers of ELBW children with developmental difficulties may be a result of the three paths of stress formation. Firstly, these mothers may experience loss of resources over the years in different ways. For example, raising a child with a disability can affect marital adjustment (Saigal et al., 2000), and physical and mental quality of life (Witt et al., 2012). Secondly, these mothers may experience a threat to their existing resources, such as uncertainty about the child’s future (Taylor et al., 2000). Thirdly, while some of these mothers have limited options to gain more resources, they may experience investment in resources without knowing if they will be rewarding. For example, investment in a child with intellectual disabilities may yield limited results as compared with such investment in a child with normal intelligence (Graungaard, Andersen, & Skov, 2011).

Our next finding was that about a quarter of the mothers of ELBW children were qualified for a diagnosis of PTSD as suggested by the self-report PPQ-II. Although this study did not include a normative comparison group, the reported rate is still higher than...
the estimated prevalence of PTSD in the general population, which is about 8% (American Psychiatric Association, 2000). The rate observed in this study is also similar to those reported in samples of mothers in NICU after birth (23%; Vanderbilt, Bushley, Young, & Frank, 2009), mothers of 6 months VLBW infants (24%; Feeley et al., 2011), mothers of 18 months low-risk pre-term infants (26%; Pierrehumbert, Nicole, Muller-Nix, Forcada-Gux, & Ansermet, 2003) and parents of VLBW infants 3.5 years post-natal (20%; Elklit et al., 2007). Thus, our results suggest that the birth of an ELBW infant and the period subsequently spent in the NICU may be related to PTSD symptoms in mothers, 4–16 years after birth. The empirical literature points to a number of possible factors contributing to PTSD symptoms among mothers of premature infants. In general, symptoms may occur because of the early birth and the stay in the NICU that brings concern for the infant, exposure to medical procedures that might cause suffering, and feelings of helplessness and uncertainty (Ahlund et al., 2009; Shaw et al., 2009). In addition, mothers may feel loss of control over events and their role as sole decision-makers for their children (Karatzias et al., 2007). For example, a study carried out 3 years after birth found that most mothers of premature infants (<37 weeks) reported vivid memories of stress related to the infant’s appearance and behaviour, the medical procedures and pain the infant experienced, the changes in their role as mothers during their stay in the NICU and future concerns about the outcomes of prematurity (Wereshczak, Miles, & Holditch-Davis, 1997).

Contrary to our hypothesis we did not find significant differences in PTSD symptoms as related to severity prematurity developmental outcomes. This finding is not consistent with other studies in the first years after birth (Elklit et al., 2007). For example, during the 3-year study, mothers of high-risk infants with VLBW reported higher levels of anxiety symptoms than mothers of low-risk infants with VLBW and term infants. Given the high prevalence of PTSD symptoms among the total sample, it is possible that mothers of ELBW children have the potential to suffer from PTSD symptoms after birth and the stay in NICU that may be maintained over the years, regardless of the development of the premature infant. As a number of studies found that the extent of the child’s disability or health condition may explain mothers’ PTSD symptoms up to 3 years after birth (Feeley et al., 2011), there is a question regarding the reasons for this pattern of results. One possibility is that mothers may experience the complexities and difficulties of raising a child with a disability as a more stressful but less traumatic event. A mother can still suffer from intrusive thoughts regarding the birth and stay in NICU, but the demands of everyday life facing prematurity developmental outcomes may bring continuous stress. Furthermore, mothers probably experienced many stressful events in their lives since the trauma of birth that might be experienced as more remote. It is also worth noting that we found a trend of results that is compatible with our hypothesis but it did not reach significance, probably due to the low number of participants.

Our last aim was to examine an integrative model predicting mothers’ perceived stress and PTSD symptoms. Among the sociodemographic variables, we found a link between level of maternal education and mothers’ stress, which is consistent with previous studies. For example, two recent studies found that the lower the mother’s education, the higher her perceived stress at 8–18 months (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011) and 4 years after births (Ong, Chandran, & Boo, 2001). It is possible that mothers’ lower level of education is related to less access to sources of information and support that increase their stress (Davis, Edwards, Mohay, & Wollin, 2003). Previous studies also found that the number of children is related to stress and strain among mothers (e.g. Brummelte et al., 2011). Therefore, the more children in the family, the less available mothers are to process the trauma of birth, thus affecting the consolidation and chronicity of PTSD symptoms. Accordingly, we found that the more mothers experience adverse life events after birth, the higher the probability they would suffer from perceived stress and PTSD symptoms, 4–16 years after birth. These findings are consistent with literature showing that the negative life events may exacerbate existing psychopathology (e.g. Barlow, 1988) and specifically PTSD (Solomon & Flum, 1988). However, our study is the first to take into account maternal negative life events and to examine their contribution to the emotional condition of ELBW children’s mothers several years after birth. Thus, exposure to negative life events can lead to depletion of accumulated resources and might conclude with adjustment difficulties (Robertson, Morse, & Baird-Thomas, 2009).

In the final model, we found that the severity of prematurity developmental outcomes made a significant contribution to mothers’ perceived stress, above and beyond the level of education and negative life events after the birth. We suggest that the period of late childhood may represent a peak of accumulated stress in the ELBW mothers’ lives. After this peak, during early adolescence, mothers’ child-related stress seems to equal the stress of term-children mothers (Singer et al., 2010). According to the COR theory, once initial losses occur people become vulnerable to more losses. This negative effect termed ‘loss spirals’ points to the fact that people deplete their resource pool and use ineffective coping strategies in their attempts to avoid loss of resources (Hobfoll, 2001). Thus, mothers’ loss spiral begins with premature birth and the long stay in NICU that usually is accompanied by feelings of grief and mourning (Rogers & Hogan, 2003). Next, most mothers are faced with parenting of children with
serious developmental difficulties and disabilities (Lorenz, 2001) that can spill over into other life domains such as marriage, economic stability and occupation (Cronin, Shapiro, Casiro, & Cheang, 1995). It may be assumed that the accumulated nature of these stressors affects the perceived stress of mothers more than the unique contribution of each stressor by itself.

There are some limitations to the current study. Firstly, the use of self-report measures, although very common in trauma studies, entails the risk of a reporting bias. Future studies should consider gathering data from multiple informants such as the participant psychiatrist and making use of objective measures, such as observation of mothers’ actual functioning. Specifically, it is worth noting that although ‘severity of prematurity developmental outcomes’ index was introduced in previous studies among this population (e.g. Steinmacher et al., 2008), it is still exploratory. Secondly, we were not able to include a comparison group of mothers of VLBW and term children that might help understand the relations between developmental difficulties and mothers’ stress on the wide spectrum of prematurity. Thirdly, the lack of pre-birth assessment of stress and PTSD symptoms strongly limits our ability to infer causality. Fourthly, due to technical reasons, we were not able to collect data about the length of stay in the NICU. This information is important because of its relation to the degree of exposure to stress and PTSD. Fithly, our sample was drawn from a major Israeli medical centre. It is possible that inclusion of more medical centres could have improved the generalizability of the findings. Sixthly, our sample was relatively small and might reduce the power of our results. However, the homogeneity of the group reduced somewhat the need for a larger sample size. Last, we assessed mothers in a wide range of years after birth (4–16 years). The demand characteristics and stress associated with caregiving in these different developmental periods might be dissimilar.

To conclude, the findings of this study suggest that there is an association between severity of prematurity developmental outcomes and the perceived stress of mothers of ELBW children, but not their PTSD symptoms. Thus, mothers of developmentally delayed ELBW children perceive more stress than mothers of normally developing ELBW children. Furthermore, mothers of ELBW children have the potential for PTSD symptoms, 4–16 years after birth. Most intervention programs focus on the immediate post-partum period, including the assumption that maternal stress is most prevalent during this period (Glazebrook et al., 2007). Some of these studies reported about promising effects of early interventions on parental stress, up to 3 years after birth (e.g. Kaarensen, Rønning, Ulvund, & Dahl, 2006). Based on the findings of this study, it is important to investigate the amount of stress after early intervention, but also whether later intervention can reduce the long-term stress in these mothers. Furthermore, our results highlight the importance of providing tools and emotional support to these mothers throughout this period.

REFERENCES


