Abstract

Objective: The present study is a literature review to identify the effects of a very low birth weight newborn on family. This is an important instrument to clarify epidemiological issues and to suggest the directions for health policy efforts.

Method: A three-step review was carried out using databases of journals indexed for Medline/Lilacs/Scielo/Cochrane published between 1966 and 2005 using specific criteria of inclusion. The first step selected 12 articles from 2,889 when searching for the keyword “very low birth weight infant”; the second step used the crossing of keyword “premature infant” with other pertinent keywords and terms resulting in 191 articles generating 7 more articles matching the criteria of inclusion. The third step was to analyze the references of articles in steps 1 and 2 (12 + 7 = 19), selecting 3 additional ones totaling 22 selected articles.

Result: Evidences in literature state that the families of very low birth weight newborns suffer potential negative effects on their operational dynamics, which is associated to the clinical seriousness, the age and the neuropsicomotor development of such children. It seems that the mother is the most affected member due to the situation imposed to the family, and the one who needs psychosocial support more frequently.

Conclusion: The number of existing studies is still insufficient to clarify whether the effects on the family considering all their aspects are preponderantly positive or negative.


Key words: Very low birth weight infant. Premature infant. Family. Stress. Stressful events. Life change events. Review literature.
Introduction

An expressive increase of the survival rate among very low birth weight newborns (VLBW) with birth weight less than 1,500 g, receiving intensive care has been registered over the last 25 years1,2.

According to Rugolo3, to take care of a newborn with VLBW, besides guaranteeing the survival and minimizing the immediate morbidity, implies also in a favorable outcome. In this context, researchers started to question the quality of life of such surviving premature infants, once the increase of survival rates was not followed by the fall of newborn morbidity, what led to a big increase of survivors and a greater frequency of diseases in VLBW newborns.

Therefore, the increase of survivors among VLBW newborns brings up the long-term neuropsychomotor development issue4, especially during the integration period at school7, which is the first step towards the good quality of life in adulthood8,9.

These findings lead to questions on the preparation the families have to receive, welcome and take care of a VLBW newborn. Would the families of such infants promote changes in their family dynamics during the admission period of their children and by the time of hospital discharge?

What are the effects caused by the arrival of a VLBW newborn with or without neuropsychomotor disturbance on the family structure? Would this impact be economical (changes in the family economic condition), social (quality and quantity of relationships with nonmembers of the family), familial (quality of relationship among members of the family), individual (the subjective idea experimented by any individual) or an association of all these factors? Are the families of these children prepared for these effects or would they need some kind of assistance? Would there be enough studies to describe and elucidate these issues?

Historical records

Medicine developed fast during the XIX and XX centuries. The acceleration of this evolution brought transformations in the whole context of the world health care. Regarding the assistance to children, one of the main chapters of this history is the establishment of Newborn Intensive Care Units (NICU).

In the past, the attention to newborns was limited to the well-intended actions to promote their survival by their parents, midwives and doctors10. Efforts aimed at providing an environment similar to the intra-uterine one and all energies were focused to three basic supporting needs: temperature, nutrition and protection against infections11. The interest of industry enabled investigation, discovery and improvement of equipment, drugs and nutrients, contributing along with the scientific community for the establishment of NTICUs12, and consequently the world started to experiment a constant improvement of equipment, drugs and nutrients, minimizing the immediate morbidity, implies also in a greater frequency of diseases in VLBW newborns.

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Objective

The objective of this study is to identify the effects of a VLBW newborn on family. It turns out to be an important instrument to clarify epidemiological issues of such population and to suggest the directions for health policy efforts in order to promote a better quality of life for these children, their families and society.

Methodology

The literature review was done in three steps. The first consisted of listing 2,889 articles from Medline, Lilacs, Scielo and Cochrane Library databases using the keyword “very low birth weight infant”. From this total we selected 12 articles that matched the following inclusion criteria:
• Original article published in the period between 1966 and 2005;
• Cohort, case-control and cross-sectional studies;
• Researches describing the characteristics of families of premature infants or families of VLBW newborns.

The second step consisted of combining the key words “premature infant” with each of the following key words and terms:

Key words: psychosocial impact; family; stress; stressful events; life change events; adjustment disorders; depression; maternal.
Terms: family impact; social impact; extremely low birth weight; parental stress; parental attitudes; stress psychological.

With this second procedure we obtained 191 articles and based on the same inclusion criteria linked above, 7 more articles were selected.

Finally, the third step was to review the references of the 19 (12 + 7) selected articles in first and second steps, in order to identify more articles that fulfilled the selection criteria. Thus, in this step we identified 3 additional articles. The final number of reviewed articles were then, 22 (12 + 7 + 3).

Duplicate articles were accounted for just once.

Discussion

We found a Kaplan & Mason study published in 1960 that described the birth of premature infant as an acute emotional crisis for the mother; however this assessment was restricted to mothers of premature infants. Later on, other studies showed some concern as parents and children suffering.

In the past, the first comparative studies identified analyzed mothers’ reactions to pre-term infants with distinct methodologies (different cutoff points concerning birth weight and different times for data collection). Smith et al. assessed 35 mothers of pre-terms (birth weight between 1,400 and 2,500 g) and 35 mothers of full-term infants (birth weight higher than 2,500 g) from a psychiatric point of view, and results showed no significant differences between groups of the first week postpartum. Nevertheless, Choi in 1970 compared 20 mothers of pre-terms to 20 mothers of full-term infants, also in the first week postpartum and found significantly higher levels of depression and anxiety in the mothers of premature infants.

Parents’ emotional response after the first week postpartum was initially studied by Jeffercoat et al. who adopted unusual cutoff points for birth weights of newborns. They interviewed 17 families of pre-term infants (birth weight between 1,200 and 2,100 g) and 17 families of full-term infants (birth weight more than 2,500 g) between their children’s 6th to 20th month of life. Although the study had shown that the pre-term birth of an infant produced emotional disturbances, delayed or inadequate maternal attachment and undue problems in caring for the infant at home for both parents compared to a full-term birth, a number significantly higher of negative emotions in mothers were found when compared to fathers of the same group.

On the other hand, Trause & Kramer in 1980 studied 38 parents of 19 low-risk pre-term infants and 28 parents of 14 healthy term infants, and found that parents of full-term infants experimented significantly more depression and emotional disturbances than parents of pre-term infants at 1 month postpartum. However, Scheiner et al. in 1985, found no differences in the depression level of 17 mothers of full-terms and 17 mothers of pre-term infants when their children were 12 to 18 months old.

The main researchers’ concern on the above mentioned was understanding the effects the birth of a pre-term infant on their parents and whether they were ready to receive this infant within the family environment. Nevertheless, studies until then produced inconsistent and inconclusive results according to Gennaro, who consequently, realized a longitudinal study. He examined 41 mothers of pre-term infants (birth weight between 1,000 and 2,500 g) and 41 mothers of full-term infants (birth weight more than 2,500 g) in the immediate postpartum period (1 week) and over time (first 7 postpartum weeks) using the State-Trait Anxiety Inventory (STAI) and the Depression Adjective Check List (DACL). Results showed mothers of premature infants had heightened anxiety and depression in the first postpartum week than mothers of control group. However, this difference disappeared during the second to the seventh postpartum weeks and still mothers did not experience differences in anxiety and depression based on the level of illness of their infant. In another follow-up case, Lambrenos et al. investigated depression in 96 mothers: 30 of premature infants at risk for the development of cerebral palsy, 35 of premature infants considered not to be at risk for the developing cerebral palsy and 31 of healthy full-term infants. They found equally high levels of depression in all three groups of mothers throughout the first year of the children’s lives.

We observed that researchers concentrated their efforts on assessing the prevalence of depression, anxiety and emotional disturbances of premature newborn parents, mainly the mothers, thus limiting the analysis of the contextual process of caring for an infant that, besides the individual aspects of parents, also included the financial, social and environmental aspects of the whole family. Additionally, the heterogeneity of the studies regarding children’s birth weight ranges, as well as the instruments utilized, limit the analysis of results found.

We identified the survey by Rivers et al. as the first study that specifically assessed, the effects of a VLBW newborn on family and the first study considering other variables in addition to parents’ individual aspects. Researchers interviewed the parents of...
VLBW newborns with an average age of 4.3 (three to seven years) presenting neurological abnormalities (17 brain paralysis and five hydrocephaly), parents of VLBW children without neurological sequelae. The comparison of results indicated that the costs with medical care were frequently higher for the families of children with neurological abnormalities than for the families of normal children; VLBW children with neurological abnormalities demanded more hospitalization after birth than the ones in the group of normal children; and the families of children with neurological abnormalities registered significantly more stress due to medical doubts not clarified when compared with the control group (table I).

Brook et al.40 returned to focus parents’ individual aspects and followed 47 mothers of VLBW newborns, using The Multiple Affect Adjective Checklist44. They found that these mothers were significantly more anxious and depressed before their infants were discharged from hospital than when the infants were 9 months old. However, Lee et al.41 using a scale for measuring the impact on family45 when comparing information supplied by three groups of VLBW newborn parents newborns with development quotient (DQ) measured by Griffiths Mental Development Scales: 1) DQ less than 80; 2) DQ more than 80, and 3) normal birth weight by the time children presented an average age of 36.5 months (12 to 72 months), showed that the parents in 1) presented no worse impact than those in 3), however the ones in 2) presented a more positive impact (less score) than the two other groups.

Cronin et al.42, using the same scale for measuring the impact on family45, compared families of VLBW newborns with families of normal birth weight newborns (age between one and five years) and found significant differences in score for all items of impact (economical, social, familial and individual) showing that the families of VLBW newborns, mainly those with lower DQ measured by Gesell Development Scales46 suffer a more negative impact (higher score) than the families in control group.

Collins et al.43, using a structured questionnaire, compared two groups of Afro-American mothers (VLBW newborns and normal weight newborns) and identified that the mothers of VLBW newborns presented more stressful events and expressed unfavorable overall perception of their residential environments.

Subsequently, studies returned to focus parents’ individual aspects, but keeping the reference of VLBW infants. Singer et al.44 compared three groups of mothers with newborns in their first month of life (VLBW newborns with bronchopulmonary dysplasia (BPD); without BPD and normal birth weight) and found more psychological distress in mothers of the 2 first groups than in mothers of normal birth weight newborns.

In the same manner, Halpern et al.45 and Ong et al.46 found a higher prevalence of maternal stress in families of VLBW newborns when compared to families of normal birth weight newborns, respectively at 9 months and at fourth year of their children’s lives.

Taylor et al.47 compared 3 groups of families (families of newborns with birth weight less than 750 g; with birth weight between 750 to 1,499 g and with normal birth weight) and found that families of the first group presented more stress in relation to the control groups and newborns with greater neonatal risk presented more negative impacts on their families.

In the same year, Prindham et al.48 studied mothers of newborns with BPD and without BPD and with normal birth weight, and found more symptoms of maternal depression in the families of VLBW newborns with BPD in comparison to the two other groups.

Recently, Kerstig et al.49, in a prospective longitudinal study compared the posttraumatic stress response of 50 mothers after the birth of a VLBW infant with 30 mothers of healthy term infants, at four measuring time points (1-3 days postpartum, 14 days postpartum and 6 e 14 months postpartum) using the Impact of Event Scale (IES-R), psychometric instruments (Structured Clinical Interview for DSM-IV, SCID-I), Back Depression Inventory (BDI), Montgomery Asberg Depression Scale (MADRS), State-Trait Anxiety Inventory (STAI) and Hamilton Anxiety Scale (HAMA). At all four measuring time points (except 6 months postpartum), the mothers of VLBW infants recorded significantly higher values for traumatic experience and depressive symptoms and anxiety compared to the controls. In contrast to the mothers in the control group, the mothers of the VLBW infants showed no significant reduction in posttraumatic symptoms (IES-total), even 14 months after birth.

Padovani et al.50, in a Brazilian study assessed 43 mothers of VLBW infants without a psychiatric background using STAI and BDI in two moments: during the hospitalization of infant and after the discharge. After infants’ discharge, the number of mothers with clinical level of emotional symptoms decreased significantly in comparison to the first assessment. The anxiety-state level decreased significantly from the first to the second assessment. No differences in depression and dysphoria symptoms between two assessments were found.

We also found studies that assessed the impact on families, more specifically, on survival of newborns with extreme low birth weight (ELBW —birth weights less than 1,000 g). Stjernqvist51 interviewed parents of ELBW, found more reactive crises in mothers than in fathers and stated that parents of these newborns reported more stress during the first year of child’s life, what causes more tension in marital relationship when compared to the control group comprising fathers of newborns with normal weight; however the same study identified no relation between permanent neurological disturbances in childhood and strong reactions by the members of the family (table II).

Nevertheless, Saigal et al.52 compared families of ELBW newborns with families of pre-terms infants.
### Table I

Articles indexed for Medline, Lilacs, Scielo and Cochrane Library databases that analyze the VLBW* newborns impact on their families

<table>
<thead>
<tr>
<th>Author/Country</th>
<th>Study design</th>
<th>Casuistic</th>
<th>Economic and social dimensions</th>
<th>Familial and personal strain dimensions</th>
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</thead>
<tbody>
<tr>
<td>Rivers et al. (1987)* USA</td>
<td>Cohort</td>
<td>(22 parents of VLBW* newborns neurologically abnormal / 15 parents of VLBW newborns neurologically normal) Average age 4.3 years (range 3-7 years)</td>
<td>Cost of later medical care was a problem (41%/13%) p &lt; .05</td>
<td>Stress due to medical terms not explained (32%/7%) p &lt; .05 Rehospitalizations (81.8%/40%) p &lt; .01</td>
</tr>
<tr>
<td>Brooten et al. (1988)* USA</td>
<td>Cohort</td>
<td>(47 mothers of VLBW newborns before infants’ discharge / infants were 9 months old)</td>
<td></td>
<td>Anxiety (6.83/4.27)# p &lt; .05 Depression (11.27/9.14)# p &lt; .01</td>
</tr>
<tr>
<td>Lee et al. (1991)* Canada</td>
<td>Cohort</td>
<td>(33 parents of VLBW newborns DQ** &lt; 80 / 139 parents of VLBW newborns DQ &gt; Average age 36.5 months (range 12-71 months)</td>
<td>Score financial (9,1/7,9/8,9)# p &lt; .01</td>
<td>Score family (19,2/17,1/19,6)# p &lt; .05 Score Mastery (8,8/8,9/9,0)# p &lt; .05</td>
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<tr>
<td>Cronin et al. (1995)* Canada</td>
<td>Matched</td>
<td>(96 parents of VLBW newborns / 96 parents of full term infants)</td>
<td>Impact on family - Total scores (50,4/45,1/50,6) - p &lt; .05</td>
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<tr>
<td>Collins et al. (1998)* USA</td>
<td>Cohort</td>
<td>(28 mothers of VLBW newborns / 52 mothers of full term infants) Average age (range 2-4 years)</td>
<td>Unfavorable overall perception of residential environment (OR' = 3,2) p &lt; .05</td>
<td>Stressful life events during pregnancy (OR = 3,1) - p &lt; .05</td>
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<tr>
<td>Singer et al. (1999)* USA</td>
<td>Prospective Cohort</td>
<td>(206 mothers of VLBW newborns with or without BPD*** / 123 mothers of full term infants) Follow-up – 3 years</td>
<td>Psychological distress (13%/1%) p = .03</td>
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<tr>
<td>Halpern et al. (2001)* USA</td>
<td>Cohort</td>
<td>(23 parents of VLBW newborns / 33 parents of full term infants) Age – 9 months</td>
<td>Maternal stress (VLBW &gt; full term) p &lt; .05</td>
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<tr>
<td>Ong et al. (2001)* Malaysia</td>
<td>Cohort</td>
<td>(116 mothers of VLBW newborns / 96 mothers of full term infants) Age – 4 years</td>
<td>Maternal stress (39,7%/20,8%) p = .003</td>
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<tr>
<td>Taylor et al. (2001)* USA</td>
<td>Cohort</td>
<td>[59 parents newborns (&lt; 750 g) / 53 parents newborns (&gt; = 750 g e &lt; 1,500 g) / 44 parents of full term infants] Average age 7 years</td>
<td>Familial stress (61%/51%/32%) p &lt; .05</td>
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<td>Pridham et al. (2001)* USA</td>
<td>Cohort</td>
<td>(31 mothers of VLBW newborns with BPD / 23 mothers of VLBW newborns without BPD / 49 mothers of full term infants) Follow-up – 1 year</td>
<td>Maternal depression (VLBW with BPD &gt; controls groups) p &lt; .05</td>
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<td>Kersting et al. (2004)* Germany</td>
<td>Cohort</td>
<td>(50 mothers of VLBW newborns / 30 mothers of healthy term infants) Follow-up – 14 months</td>
<td>Traumatic symptoms (VLBW &gt; healthy term) p &lt; .05</td>
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<tr>
<td>Padovani et al. (2004)* Brazil</td>
<td>Cohort</td>
<td>(43 mothers of VLBW infants during hospitalization / after hospitalization)</td>
<td>Anxiety-state level (35%/12%) p c = .006 Emotional symptoms (44%/26%) - p c = .008</td>
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* VLBW = Very low birth weight (< 1,500 gm).
** DQ = Developmental quotients.
***BPD = Bronchopulmonary dysplasia.
†The results relating to the impact on family scale revisited:
Economic and social dimensions / Familial and personal strain dimensions.
‡The results relating to the multiple affect adjective checklist, where the higher score indicates more effect.
§Prevalence.
¶OR = Odds Ratio.
*§§Score relating to the impact on family scale revisited, where the higher score indicates more negative family impact.
from the same social-demographic condition and found that the positive effects as much as the negative ones on marital relationship were more frequent in the families of ELBW newborns. Additionally, neurologi-
cal sequelae in children with ELBW promote difficulties in the familial context, in spite of causing a refine-
ment of parents’ feelings about themselves, concluding that parents of ELBW newborns adjusted

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<tbody>
<tr>
<td>Stjernqvist (1992)</td>
<td>Prospective</td>
<td>(20 parents of ELBW* newborns / 20 parents of full term infants)</td>
<td>Maternal physical symptoms (75%/55%) p &lt; .003</td>
<td>Maternal disturbances (58%/21%) p &lt; .05</td>
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<tr>
<td>Sweden</td>
<td>Follow-up – 1 year</td>
<td>(26% with neurological sequelae)</td>
<td>Own emotional health affected (21%/9.8%) p &lt; .05</td>
<td>Marriage relationships - stress/strains (14%/5.7%) p &lt; .005</td>
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<td></td>
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<td>(123 parents of full term infants)</td>
<td>Negative effects on other children (21.6%/7.1%) p &lt; .005</td>
<td>Decision on not having other children (58.3%/6.3%) p &lt; .005</td>
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<td>(2% with neurological sequelae)</td>
<td>Less parental attention (14.4%/3.6%) p &lt; .05</td>
<td>Improved their feelings about themselves (56.3%/42.5%) p &lt; .05</td>
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<td></td>
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<td>Age (range, 12-16 years)</td>
<td>Decision on not having other children (54%/39%) p &lt; .05</td>
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<td>Saigal et al. (2000)</td>
<td>Cohort</td>
<td>[145 parents of ELBW newborns / 123 parents of full term infants]</td>
<td>Friends and relatives are more comprehensive and helpful (53.5%/25.2%) p &lt; .001</td>
<td>Own emotional health affected (21%/9.8%) p &lt; .05</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
<td>(26% with neurological sequelae)</td>
<td>Unable to take a job (7.6%/0.8%) p &lt; .05</td>
<td>Decision on not having other children (58.3%/6.3%) p &lt; .005</td>
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<td>Age (range, 12-16 years)</td>
<td>Marriage relationships - positive effects (21%/7%) p &lt; .001</td>
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<td>Marriage relationships - negative effects (14%/6%) p &lt; .001</td>
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<td>Positive interactions with family (37%/13%) p &lt; .001</td>
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<td>Improved their feelings about themselves (74%/51%) p &lt; .05</td>
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<td>Emotional health affected (34%/17%) p &lt; .05</td>
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<td>Negative effects on other children (45%/14%) p &lt; .001</td>
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<tr>
<td>Saigal et al. (2000)</td>
<td>Cohort</td>
<td>(110 parents of ELBW newborns / 120 parents of full term infants)</td>
<td>Positive interactions with friends (51%/25%) p &lt; .001</td>
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<td>Canada</td>
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<td>without impairments / without impairments</td>
<td>Marriage relationships - positive effects (21%/7%) p &lt; .001</td>
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<td>Age (range, 12-16 years)</td>
<td>Marriage relationships - negative effects (14%/6%) p &lt; .001</td>
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<td>Negative effects on other children (45%/14%) p &lt; .001</td>
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<tr>
<td>Tommiska et al. (2002)</td>
<td>Sectional</td>
<td>(56 mothers of ELBW newborns / 66 mothers of full term infants)</td>
<td>No significant differences were found</td>
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<tr>
<td>Finland</td>
<td>Age - 2 years</td>
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<tr>
<td>Tommiska et al. (2002)</td>
<td>Sectional</td>
<td>(23 fathers of ELBW newborns / 38 fathers of full term infants)</td>
<td>No significant differences were found</td>
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<tr>
<td>Finland</td>
<td>Age - 2 years</td>
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<tr>
<td>Tommiska et al. (2002)</td>
<td>Sectional</td>
<td>[All mothers (122) / All fathers (61)]</td>
<td>Distress regarding social isolation (1.94/2.14%) p = .04</td>
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<tr>
<td>Finland</td>
<td>Age - 2 years</td>
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<td>Distress regarding role restriction (3.77/3.94%) p &lt; .008</td>
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<td>Distress regarding incompetence (2.21/1.95%) p = .0011</td>
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<td>Distress regarding relationship problems (2.39/2.1%) p &lt; .018</td>
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</table>

* ELBW = Extremely low birth weight (< 1,000 gm).
†The results relating to the impact on family scale revisited†: Economic and social dimensions / Familiar and personal strain dimensions.
‡Prevalence.
§Score relating to the SPSQ – Swedish Parenthood Stress Questionnaire, where the higher score indicates more stress.

Table II
Articles indexed for Medline, Lilacs, Scielo and Cochrane Library databases that analyze the ELBW* newborns impact on their families
reasonably well their works and family responsibili-
ities and that, although some negative effects had been
identified, there was still considerable preparation for
the active treatment of their children.

Subsequently, Tommiska et al. using the Swedish
Parenthood Stress Questionnaire (SPSQ) found no
significant differences when comparing mothers of
ELBW newborns to mothers of full children, or when
comparing fathers of ELBW newborns to fathers of
control group. Nevertheless, differences were found
when all mothers were compared to all fathers. Moth-
ers indicated significantly more distresses regarding
the functional restrictive part and their children’s inca-
pacity in addition to the marital relationship problems;
however fathers indicated significant more distresses
regarding the social isolation this situation imposes

Conclusion
The data analysis leads to the conclusion that the fa-
milies of VLBW newborns suffer potential effects on
their daily dynamics, which relates to the clinical se-
riousness, age and neuropsychomotor development of
such children. It seems that the mother is the most af-
ected member of the family due to the situation im-
posed to the family, and who more frequently needs psy-
chosocial support, mainly during the first week of life
and before the discharge. The lines of research lead us
to understand that the families of VLBW newborns
with development disturbances suffer negative im-
 pact, complicating the handling of such situations. On
the other hand, the families of VLBW newborns with
or without neuropsychomotor development disturban-
ces suffer a positive impact in comparison to new-
borns with normal birth weights. Nevertheless, the
number of existing studies is still insufficient to cla-
 rify whether the effects, considering all their aspects,
are predominantly positives or negatives, once the
analyzed aspects presented differences among the stu-
dies showing inconsistencies when comparing their
results. Yet, the studies selected were preponderantly
performed in developed countries, what might limit
the validity of the results when applied to developing
countries. Therefore, we concluded that new studies
should be performed in order to enhance the knowl-
edge on the effects suffered by the families of VLBW
newborns to subsidize proposals of health programs
and policies.

Concomitantly, we concluded that follow-up pro-
grams should incorporate a psychological evaluation
and support services to the VLBW newborn mothers,
immediately in the postpartum period, as well as to
provide multi-disciplinary follow-up support to these
newborns and their families. Such programs, already
a routine in other countries, are not emphasized in de-
veloping countries health policies, what hampers the
family comprehension of attendance frequency to
outpatient clinics. In line with this, some new perspec-
tives should be created in order to give support to the
families of VLBW newborns, giving them conditions
to face the challenge in order to prevent the negative
effects aiming at a better quality of life.

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