

# FEELINGS EXPERIENCED BY THE FAMILY OF AN AT-RISK NEWBORN INFANT: INTEGRATIVE LITERATURE REVIEW

SENTIMENTOS VIVENCIADOS PELA FAMÍLIA DE RECÉM-NASCIDO DE RISCO: REVISÃO INTEGRATIVA DA LITERATURA

SENTIMIENTOS VIVIDOS POR LA FAMILIA DE UN RECIÉN NACIDO DE RIESGO: REVISIÓN INTEGRADORA DE LA LITERATURA

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### **ABSTRACT**

Objective: to identify, through scientific literature, feelings experienced by the family of an at-risk newborn infant and its relationship with health professionals. Methods: this is a descriptive integrative review study. The search of papers was carried out in the databases LILACS and MEDLINE using the keywords feelings, family, and newborn infant, from August to September 2011. Initially, 18 papers were identified, out of which 14 were selected. For the analysis and subsequent synthesis of papers, a synoptic figure was used and the presentation of results and the discussion are descriptive. Results: the main feelings experienced by the family were: guilt, pity, fear, anger, helplessness, disappointment, incomprehension, and mourning due to the loss of its idealized child. Conclusions: health professionals are interlocutors in this process of conflicts experienced because of the contraposition between the idealized child and the actual child. Descriptors: Feelings; Family; Newborn Infant.

Objetivo: identificar, por meio da literatura cientifica, sentimentos vivenciados pela família de um recémnascido de risco e a relação desta com os profissionais da saúde. Método: trata-se de estudo descritivo de revisão integrativa. A busca dos artigos foi realizada nas bases de dados Lilacs e MedLine com as palavraschave sentimentos, família e recém-nascido, de agosto a setembro de 2011. Inicialmente, foram identificados 18 artigos, dos quais 14 foram selecionados. Para a análise e posterior síntese dos artigos foi utilizada figura sinóptica e a apresentação dos resultados e discussão são descritivas. *Resultados*: os principais sentimentos vivenciados pela família foram: culpa, pena, medo, raiva, impotência, decepção, incompreensão e luto pela perda de seu filho idealizado. Conclusões: os profissionais da saúde são interlocutores nesse processo de conflitos vivenciados por conta da contraposição entre o filho idealizado e o filho real. Descritores: Sentimentos; Família; Recém-Nascido.

Objetivo: identificar, por medio de la literatura científica, sentimientos vividos por la familia de un recién nacido de riesgo y su relación con los profesionales de la salud. Método: esto es un estudio descriptivo de revisión integradora. La búsqueda de los artículos fue realizada en las bases de datos Lilacs y MedLine con las palabras clave sentimientos, familia y recién nacido, de agosto hasta septiembre de 2011. Inicialmente, fueron identificados 18 artículos, de los cuales 14 fueron seleccionados. Para el análisis y la síntesis posterior de los artículos fue utilizada figura sinóptica y la presentación de los resultados y la discusión son descriptivas. Resultados: los principales sentimientos vividos por la familia fueron: culpa, pena, miedo, rabia, impotencia, decepción, incomprensión y luto por la pérdida de su hijo idealizado. Conclusiones: los profesionales de la salud son interlocutores en este proceso de conflictos vividos debido a la contraposición entre el hijo idealizado y el hijo real. Descriptores: Sentimientos; Familia; Recién Nacido.

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### INTRODUCTION

In recent decades, Brazil is experiencing an epidemiological transition process, with changes in the morbidity and mortality patterns and a significant decrease in infant mortality rates. Scientific literature has shown that this decrease was mainly due to a decline in the post-neonatal mortality rates, keeping neonatal mortality in a less significant decline.<sup>1</sup>

In this context, some Brazilian regions had their health care model recognized on a nationwide basis because they reduced the overall infant mortality rates, as in the town of Caragipe, Pernambuco, Brazil, where a marked decrease in infant mortality rates occurred: from 40.3 (1995) to 20.2 per live births (2000),and thousand implementation of the Community Health Agents Program within the Family Health Strategy was pointed out as one of the reasons.2

Birth weight is a strong predictor of neonatal morbimortality. Low birth weight children present a higher mortality in the first weeks of life. Prematurity and intrauterine growth restriction, or also a combination of both, despite various etiologies and consequences are the main causes of low birth weight.<sup>3</sup>

Technological advances in recent decades have enabled the drop in infant mortality rates, especially among the newborn infants (NBIs) with less than 1,000 g of birth weight: the survival of NIs weighing between 500 and 599 g, for instance, increased from 0%, in 1980, to almost 80% in 1993, showing a remarkable progress in reducing the mortality of extremely low birth weight babies. 1 In this sense, the modern neonatal intensive care units, equipped with the latest technology, are a milestone in the care to these babies, contributing to their survival, focusing on the biological clinical aspects, primarily. If, on one hand, these advances help increasing survival, on the other they contribute to intensify the family's difficulties and anxieties to face the care to a NBI.

Scientific literature has classified as being at risk the NBIs who present one of the following factors: residing in a risk area; low birth weight (< 2,500 g); prematurity (< 37 weeks of gestational age); severe asphyxia (Apgar < 7 at the 5<sup>th</sup> minute of life); need for hospitalization or some complication in the maternity hospital; need for special guidance at the moment of hospital/NBI care unit discharge; NBI with an adolescent mother (< 18 years); NBI with a low education mother (<

8 years); and family history of death in children < 5 years.<sup>4</sup>

Although the expected survival of high-risk children is increasing, there still remains the concern about prognosis, in the long term, since prematurity, neonatal treatment, and hospitalization time can result in children with important sequelae with regard to their development, growth, and family interaction.<sup>5</sup>

There's no step in the family cycle which causes a deeper change or poses a greater challenge than the arrival of a child. In the case of an at-risk NBI birth, either premature or sick, the family is faced with a stressful and challenging experience, which causes deep changes in the family dynamics and it's lengthened with the child's hospitalization, which often is also prolonged.

The condition of having a child implies the need for an intense personal and social restructuring and readjustment, resulting in identity change and redefinition of roles, connected to organic and psychic changes.<sup>6</sup>

In neonatal risk situations, the actual baby is different than imagined and a guilt feeling for the child's problems may act as an inhibitor factor to the spontaneous contact between parents and babies.<sup>7</sup>

The mother and family wait for a perfect child and they worry about it. Thus, many mothers, after giving birth, immediately ask to the health care team, in the delivery room, whether the child cried, whether she/he is perfect, and about her/his weight, among other questions, in order to ensure that her child was born without complications or malformations. However, when delivery is anticipated, leading to the birth of a premature baby, with low birth weight and having a possibility to develop severe complications, all dreams and desires are broken, and a new stage in the life of these families begins.

This step generates anxieties in the mother and family which can lead to emotional distress. Thus, the following question emerged: "What are the feelings experienced by the family of an at-risk newborn infant?".

This way, this study aims to identify, through scientific literature, feelings experienced by the family of an at-risk NBI and its relationship with the health professionals.

## **METHOD**

For developing this integrative review, the following steps were followed:

 Identification of the hypothesis or guiding question: it consists in

preparing a problematic situation in a clear and objective way, and then searching for the descriptors or keywords;

- Sampling selection: determining the inclusion or exclusion criteria, the moment for establishing transparency, in order to provide the selection with depth, quality, and reliability;
- Categorization of studies: definition with regard to the extraction of information from the papers reviewed, with the purpose of summarizing and organizing this information;
- Evaluation of studies: the analysis of the extracted data should be critically carried out;
- and Discussion interpretation results: the time when the main results compared and grounded on theoretical knowledge, besides the evaluation with regard its applicability;
- 6) Presentation of the integrative review and knowledge synthesis: one should address the information from each paper reviewed in a succinct and systematized manner, presenting the evidence found out.<sup>8</sup>

To guide this integrative review, the following research question was prepared: "Among the contributions produced in the national scientific literature, what is the available evidence on the feelings experienced by the family of an at-risk newborn infant?".

Regarding the literature survey, two databases were consulted: LILACS (Latin American and Caribbean Health Sciences Literature) and MEDLINE (Medical Literature Analysis and Retrieval System Online).

The search was conducted from August to September 2011, through online search. Access to the full papers occurred through the SciELO (Scientific Electronic Library Online) or CAPES (Coordination for the Improvement of Higher Education Personnel) websites.

The criteria for inclusion of papers initially defined for this integrative review were: a) papers published in Portuguese with abstracts available in the selected databases; b) papers published in the period between January 2000 and December 2011; c) full papers available in the SciELO or CAPES websites; and d) papers addressing the theme feelings experienced by the family of an at-risk NBI.

Due to specific characteristics for accessing the two selected databases, the strategies used to find papers were adapted to each one, having as a guiding axis the question and the inclusion criteria for the integrative review, previously established, to maintain coherence in the search for papers and avoid possible biases.

The keywords used were: feelings, family, and newborn infant. The search was conducted through online access, using the four inclusion criteria, and, initially, 18 papers were identified; after analyzing the abstracts, 4 papers were excluded, since they don't meet the inclusion criteria, and the final sample of this integrative review consisted of 14 papers.

For data collection from papers, an instrument was designed, and it underwent visual and content validation by three judges. Three teachers at a public university were the judges, they're experienced with regard to the theme under study and/or the assessment of instruments and provided suggestions for changes in the instrument, which were mostly implemented. The final instrument includes the following items: paper title, authors' identification, professional category, journal title, publication year, study site, database, intervention studied, methodological design, evidence level, results, and recommendations and/or conclusion.

For the analysis and subsequent synthesis of the papers which met the inclusion criteria, a synoptic figure specially designed for this purpose was used, addressing the following aspects: the research title; authors name; intervention studied; results; and recommendations/conclusion.

The presentation of results and discussion of data was carried out in a descriptive manner, allowing the reader to evaluate the applicability of the integrative review developed, in order to achieve the aim of this method.

## **RESULTS**

In this integrative review, fourteen papers which met the inclusion criteria previously established were analyzed, then, an overview of the papers reviewed is presented.

Among the papers included in this study, 7 were written by nurses, 1 has nurses, physicians, and sociologists among its authors, 1 was written by a physical educator and a nutritionist, 1 was written by nurses and dentists, 1 was written only by physicians and nurses, and with regard to 3 papers it wasn't possible to identify the professional category of their authors.

Regarding the publication year, 1 occurred in 2000, 2 in 2004, 2 in 2006, 3 in 2007, 2 in

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2008, and 4 in 2010. Concerning the database, 11 are indexed in LILACS and 3 in MEDLINE.

Out of the reviewed papers, 12 were developed in hospital institutions, 1 at the family's home, and 1 in a Support House. It was also found out that the 14 researches were carried out in single institutions. Regarding the type of journal in which the papers were published, 11 were published in General Nursing journals, 1 in a Medicine journal, 1 was published in a Nutrition journal, and 1 was published in a General Health journal.

Analysis with regard to the research design of the papers studied showed that 12 papers carried out descriptive studies performed with a qualitative approach, 1 was a descriptive study with a quantitative approach, and 1 was a case report. Thus, with regard to the level of evidence obtained in the papers, it was found out that 13 belonged to level 4 and 1 to level 5, respectively.

In figures 1 to 5 the synthesis of papers included in this integrative review is shown.

Title	Author	Interventions studied	Results	Recommendations/conclusion
Interviewing the families of sick newborn babies as a proposal of nursing assessment and intervention	Fernandes MGO, Viana DL, Balbino FS, Horta AL <sup>8</sup>	To know, through interview with parents of a malformed newborn infant, the experience of this moment in the family life cycle, in order to seek measures of nursing intervention in families in this situation coming from the process experienced.	The birth of a malformed newborn infant generates various feelings in the family, such as mourning due to the loss of the idealized child, guilt, and shame, and it can cause conflicts and family instability, affecting the management of the care to be provided to the newborn infant.	The nurse's role as a member of the interdisciplinary team was shown and the need for interventions designed with family to minimize the impact of the news and foster the expression of feelings and the crisis solution. The intervention aims to act along with the family since the problem's detection, using active listening of verbal and nonverbal communication, in an attempt to understand the situation and act as facilitator in the process of solving the crisis experienced.
Attention and care to newborn's family in neonatal unit: perspectives of health staff	Tavares AS, Queiroz MVO, Jorge MSB <sup>9</sup>	To describe the professionals' perception on the condition of being the mother of a child in the Neonatal Intensive Care Unit (NICU) and analyze the support and help strategies of professionals along with parents/family.	The impact of hospitalization and baby's stay in the NICU brings out various feelings and emotions, such as sadness, fear, pity, guilt, helplessness, hope, and others. Often, the sense of loss and doubts about the child's survival lead parents to stand back, developing a negative reaction with regard to the child, and it can compromise their participation in the follow-up to their child during hospitalization.	The study showed that the professionals demonstrated sensitivity to the mother's situation and the need for intervening with parents, facilitating the expression of feelings and the exchange of information, because, this way, they can contribute to the child's treatment. Not all professionals, however, dedicate themselves to these moments, which are very adequate to safeguard and protect the physical and mental health of the mother/family and the child her/himself.

Figure 1. Synthesis of the papers included in the integrative review.

Title	Author	Interventions studied	Results	Recommendations/conclusion
Achieving exclusive breastfeeding of premature babies: the perceptions and experience of women from public health services	Braga DF, Machado MMT, Bosi ML <sup>10</sup>	To investigate perceptions and experiences of mothers of premature newborn infants who exclusively breastfed from the 4 <sup>th</sup> to 6 <sup>th</sup> month of life.	The birth of a premature child leads to a great shock to the parents and family, bringing up feelings of guilt, frustration, incompetence, fear, anxiety, qualm that the child can't survive, gets easily sick, or suffer side effects which promote future sequelae. And, for some mothers, breastfeeding is perceived as a must, since it can assist in the recovery of their child's health.	The study showed that the decision to breastfeed the premature newborn infant is related to recognition of the importance of mother's milk to the child's health and that exclusive breastfeeding to premature babies still remains a challenge for some mothers, but it's possible, since there's determination and adequate support from the family, social network, and, especially, health professionals.
Attachment formation between parents/preterm newborns and/or low birth weigth children using the kangaroo mother method: a contribution to nursing	Guimarães GP, Monticelli M <sup>11</sup>	To identify and analyze the promoting and complicating aspects in the bonding process between parents and preterm and/or low birth weight children during the practice of the Kangaroo Mother Method.	Promoting aspects: prenatal preparation, embracement for delivery, and participation in the neonatal everyday life.  Complicating aspects: ambiguity of feelings – frustration because the child isn't "normal, like the other ones" guilt, fear, and lack of confidence with regard to delivery and premature birth, mourning unconsciously expected (negative feelings and difficulties for adapting to the new reality), disappointment in face of the impossibility of receiving the child at birth, lack of understanding about the immaturity of the newborn infant, and the complex demand of care required.	One highlights the nurse's role as an articulator and tutor of "careful" care, not only with regard to the interaction of parents to the child, but also of the various elements of the team to each human being who is part of the family unit, planning and developing actions to allow parents to contribute to the care of their child and, gradually, gain independence during the daily transformations.

Figure 2. Synthesis of the papers included in the integrative review.					
Title	Author	Interventions studied	Results	Recommendations/conclusion	
Newborn baby in the neonatal unit: the mother's glance	Campos ACS, Odisío MHR, Oliveira M MC, Esteche CMGCE <sup>12</sup>	To identify the meaning, for the mother, of the hospitalization of a newborn child in a Neonatal Hospital Unit.	Having a child hospitalized in the NICU leads the mother to have feelings of fear, separation from her child, anxiety, and sadness.	The study showed that an effective communication channel with mothers is relevant during the hospitalization period, to alleviate the feelings coming from this experience.	
The experience lived by relatives of children interned in the neonatal intensive care units	Centa ML, Moreira EC, Pinto MNGHRP <sup>13</sup>	To identify the experience of relatives of children admitted to a NICU in a hospital in Curitiba.	Having a child admitted to the NICU leads the family to have feelings of lack of confidence, fear, anxiety, pain, and sadness.	The study showed that despite the care provided by the multidisciplinary team, the relatives feel they need more information, guidance, advice, and support.	
Maternal experience with a premature child: thinking about the difficulties of this care	Souza NL, Araújo ACPF, Costa ÍCC, Mendes Jr AM, Accioly Jr H <sup>14</sup>	To analyze maternal experiences with a premature newborn infant during the hospitalization in NICU and in the first days after hospital discharge.	The contact between mother and newborn infant in the NICU generates feelings of despair and sadness and, at the moment of discharge, the mothers refer to lack of confidence and concern with fear of domestic care.	The findings point out that prematurity needs to be worked out as a phenomenon which requires attention to the family, especially to the mother, favoring strategies to cope with this reality from the delivery moment, in the hospitalization of a child in the NICU, and, later, in the follow-up at home.	
Feelings and expectations of mothers of newborns in a neonatal intensive care unit	Melo CRM, Villa SG, Silvério NF, Santana RA <sup>15</sup>	To know the feelings and expectations of mothers of newborns infants in a NICU.	One observed that most mothers were young married adults, had a formal job, lived in Bauru, Sao Paulo, Brazil. Regarding the reaction to hospitalization, 77% were worried and distressed; 61% were concerned at the time of interview; 38.5% felt embraced and calm in the hospital environment; 84.5% reported that the relationship mother/nursing team was good; and 77% said that there was a change in their daily life.	The mothers showed feelings of worry, anxiety, calmness, and hope. Most of them believed that her child would soon be discharged from the NICU and that the treatment would be effective, demonstrating a trust relationship with the team caring for her child.	

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Figure 3. Synthesis of the papers included in the integrative review

Title	Author	Interventions studied	Results	Recommendations/conclusion
Domestic maternal experience with preterm newborn children	Souza NL, Fernandes ACP, Costa ICC, Cruz- Enders B, Carvalho JBL, Silva MLC <sup>16</sup>	To explore maternal experiences in caring for a premature newborn infant at home and analyze difficulties in maternal and child care, after hospital discharge.	The greatest difficulties faced by mothers in caring for their premature infant at home are related to food and resulted from failures of the health care team to prepare these families for home care to the premature baby. There also emerged feelings of insecurity and fear, revealing the need for a support network with outpatient follow-up and emergency care, in order to provide the families of premature newborn infants with support after discharge.	In the maternal care to a premature child at home, negative feelings which pose changes in the family, work, and social daily life prevailed, revealing the need for support for parents in the transition from hospital to home life in a prematurity situation.
The influence of support groups on the family of risk newborns and on neonatal unit workers	Buarque V, Lima MC, Scott RP, Vasconcelos MGL <sup>17</sup>	To investigate the meaning of the support group for the family of atrisk newborn infants and the professional team in the neonatal unit.	The family reports feelings of weakness, fear, guilt, anger, sadness, helplessness, and difficulty for accepting the separation posed by the child's hospitalization.	The support group for the family of at-risk newborn babies in the neonatal unit represents an approach grounded on the principles of family-driven care. Thus, it can restore parental competence, help the team to respect the parent's values and feelings, and contribute so that the parents and professionals work along in the neonatal unit.

Figure 4. Synthesis of the papers included in the integrative review.

Title	Author	Interventions studied	Results	Recommendations/conclusion
Vivência e resignificação da doença do filho recém- nascido - relato de um casal	Horta ALM, Rodrigues ARF, Seixas MRD <sup>18</sup>	To identify the meaning for the couple to have a child with cyanotic congenital heart disease.	The child's disease, his hospitalization and death generated major conflicts for the couple which interfered in its married life.	One observed that the couple's own code in the process of living the crisis related to a shock in the marital relationship, seeking to restructure and showing that they needed interlocutors for rebuilding their goals and objectives, especially after the child's death.
Experience of puerperas with hospitalized newborn children	Monteiro MAA, Pinheiro AKB, Souza ÂMA. <sup>19</sup>	To identify the puerperal women accompanying the hospitalized newborn child and know their experience in the hospitalization of a child.	The occurrence of premature birth of a baby, along with the mother-child separation, generates a conflicting situation to the puerperal woman, who feel worried and unable to understand what is going on with her and her child. The unexpected news and awareness with regard to the possibility that the child could be hospitalized brought to these mothers feelings of fear (of losing their child), anxiety, and rejection to the situation.	The understanding of relationships and the bonds established by the mother with their relatives and the group in which she's in constitutes a set of first steps so that nurses can favor their adaptation to the hospitalization process of the newborn child.
Mothers'feelings and expectations with premature child on mechanical ventilation	Cruz ARM, Oliveira MMC, Cardoso MVLML, Lucio IML <sup>20</sup>	To investigate the mothers' feelings during the hospitalization of their child in the NICU and know their expectations with regard to the treatment of a newborn infant with mechanical ventilation.	Through interaction with the children in the NICU, mothers revealed the conflicts related to their conditions. Separation is the main reason of anguish and distress, since being unable to hold the child in their arms generates a lack of confidence. However, they believe in the care and survival of a premature child, showing positive feelings and expectations with regard to hospital discharge.	The presence of mothers in the hospital environment favors monitoring the evolution of their children's health, promoting an affective bond between the mother/child binomial.
Feelings of parents facing at the birth of a premature newborn	Santos MCL, Moraes GA, Vasconcelos MGL, Araujo EC <sup>21</sup>	To analyze the feelings of parents when facing the birth of a premature newborn infant. To investigate the feelings of parents with regard to this birth during hospitalization in the neonatal unit. To understand the relationship of premature birth with the development of an affective bond between parents and newborn child. To describe the effects of premature birth on the family.	The parents' feelings are ambiguous in face of premature birth; there's a separation posed to the family by the hospitalization and prematurity is justified by divine determination.	The experience of becoming premature parents triggers ambivalent feelings, in the sense that the newborn infant's hospitalization leads to a mother's separation from the family context, besides removal from the other family members of this baby, and that, however, these parents seem to seek in religion the support to accept the actual child and keep believing in her/his recovery.

Figure 5. Synthesis of the papers included in the integrative review.

## **DISCUSSION**

Among the authors who published more papers one finds out Nursing professors. Data show that the academic body has increasingly contributed to the advancement of scientific production.

Regarding the year when papers were published, one observes that, despite it was shy, there was an increase in the number of publications addressing this theme.

The interventions studied were mostly referring to the perception of the mother and/or family about the care to the premature or very low birth weight NBI, which are regarded by the Surveillance Program of the Ministry of Health as criteria for defining a NBI as being at risk.

Regarding the purpose of this review, i.e. the feelings experienced by the family of an at-risk NBI, one observed in the papers which make up the sample that the main feelings reported were: guilt, pity, fear, anger, powerlessness, disappointment, incomprehension, and mourning due to the loss of the idealized child.

In general, the families report negative feelings and suffering with regard to the arrival of the child, often unexpected, and its complications. The papers show that these feelings, especially fear and loss of the child, interfere with the development of a bond between the baby and family, making it difficult to participate in the care to the NBI.

Another point surveyed in this review is related to the rejection of some families with regard to the "not normal" NBI, as a way to protect themselves from further suffering with the possible loss of the child due to her/his death because of complications which can emerge.

Some studies also showed that families can feel ashamed for having conceived an imperfect child, and they present a difficulty to develop a bond with this child. One notices that the family member who mostly suffers from the presence of an at-risk child are mothers, who, in general, feel guilty for conceiving an "imperfect child" and they lack confidence to care for these babies.

In some families, the birth of an at-risk NBI led to marital crises, which required support from health professionals to be overcome. It's also noteworthy that several papers addressed the importance of a support network to assist these families in accepting and coping with the situation, since they go through a great shock, which interferes with its mental health.

### CONCLUSIONS

Completing this integrative review, in search of the best evidence available, with regard to the feelings experienced by the family of an at-risk NBI, one notices that most papers report the family's negative feelings in face of the at-risk NBI and they highlight the need for support networks to work along with these families, not only during the hospitalization of their children, but also, later, at the time these NBIs are discharged and go home.

Health professionals are regarded as interlocutors in this process of conflicts experienced by family, in which the idealized child is contrasted to the actual child.

However, one finds out the existence of a few scientific works with regard to the feelings of the family in the home care provided to these at-risk NBIs, and the interventions which can be done are barely emphasized, in order to preserve the mental health of these families, helping them to overcome such a difficult and conflicting moment.

Faced with the gaps highlighted and the results pointed out in the papers included in this integrative review, one thinks it's necessary to intensify efforts to carry out researches on the theme under studv. the practice especially in of professionals, with regard to the emotional support and referral of these families to support networks, with the aim of preserving their mental health.

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