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Neonatal nursing care of the infant with congenital heart disease: an integrative review

Simone da Silveira Magalhães[1,2], Maria Veraci Oliveira Queiroz[1], Edna Maria Camelo Chaves[1]

1 State University of Ceará
2 Walter Cantídio University Hospital

ABSTRACT

Aim: To search for available evidence in the literature about nursing care for newborns with congenital heart disease in neonatal units. **Method**: An integrative review of the literature performed between July and August 2015, based on research in LILACS, PubMed and CINAHL databases. **Result**: Nine articles were identified according to established criteria. The information was analyzed and synthesized in three thematic categories: Detecting congenital heart disease; Providing care for the neonate in the intensive care unit; Family and the care measures to the newborn. **Discussion**: Neonatal screening for critical heart defects by pulse oximetry and nursing care at bedside surgeries were the main health care measures of nurses for infants with neonatal heart disease. **Conclusion**: There is a need for more professional involvement in the provision of care for these children in order to provide evidence-based clinical practice, and there are gaps in nurses' knowledge production that demonstrate this reality.

Descriptors: Heart Defects, Congenital; Nursing Care; Neonatal Nursing; Infant, Newborn.

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INTRODUCTION

Cardiac malformations are the most frequent occurrence of all congenital malformations. The prevalence of congenital cardiopathies in Brazil in 2009 was 675,495 children and adolescents, in addition to 552,092 adults. In every 1000 infants, approximately one to two present a potentially fatal cardiac issue, usually because both systemic and pulmonary blood flow depend on a patent ductus arteriosus[1,2]. Congenital heart conditions account for 24% of infant deaths and approximately 4,800 children are born each year with one of the seven critical congenital heart diseases[3]. However, infants with critical heart disease may remain asymptomatic for the first few days of life and be discharged from hospital, and their health can deteriorate rapidly at home. Therefore, early diagnosis in a timely manner is fundamental to improve prognosis and reduce morbidity and mortality rates in these cases[4,5].

Considering that congenital heart diseases are anomalies that determine the life and development of the children, and also that nursing is included in all stages of the process of health care for babies with heart disease, even in non-specialized units such as the neonatal unit, there is a need to improve the clinical practice of these professionals so that they can provide safe and evidence-based care measures.

Studies show that evidence-based practice (EBP) raises quality levels in the provision of care, improves patient outcomes, reduces costs, and brings greater satisfaction to nurses, although it is not as yet a practice implemented in many health systems around the world[6]. EBP is a movement that seeks to link theory to practice with the goal of gathering, applying and evaluating the best research results for safe clinical practice[7].

In order to fill nursing training gaps, it is expected that there will be continuing education during clinical practice with children with congenital heart diseases, using an innovative methodology supported by scientific evidence. Integrative review is one of the methods used in EBP that allows the incorporation of evidence into clinical practice. This study aimed to find the evidence available in the literature on nursing care for newborns with congenital heart disease, in the neonatal unit, with a focus on providing resources for clinical practice and directions for further research.

METHOD

An integrative review is a research method capable of synthesizing the results of previous research on a given phenomenon through a systematic and summarized analysis of the literature. It enables the identification of knowledge gaps in relation to the phenomenon under study and the need for future studies in the area[8]. According to the method, the research followed these steps: Elaboration of the research guiding question; Research in the literature of primary studies based on the inclusion and exclusion criteria; Sorting of the pre-selected studies (extraction of data from primary studies); Critical analysis of the primary studies selected; Analysis and synthesis of the evaluated results; Integration review[9].

Considering the high prevalence of congenital cardiopathies in neonatal units, especially among preterm infants, and the fact that the provision of care to these newborns presents a challenge for nurses, the following question was elaborated: "What evidence is available in the literature about the nursing care provided to newborns with congenital heart defects in neonatal units?" In order to carry out the research in the articles published between July and August 2015, we used the following databases,

accessed through the Portal of Journals of the Coordination of Improvement of Higher Education Personnel (CAPES): Latin American and Caribbean Literature of Health Sciences (LILACS), which comprises publications in the area of health in Latin America and the Caribbean; National Library of Medicine of the National Institutes of Health (PubMed), a digital archive produced by the National Library of Medicine (USA) in the Biosciences field; Cumulative Index to Nursing and Allied Health Literature (CINAHL), which contains the main scientific publications in the nursing area. Keywords and descriptors were used according to the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MESH), used in different combinations with the following Portuguese and English Boolean operators: recém-nascido, neonato, cardiopatias congênitas, unidades de terapia intensiva neonatal, unidade neonatal, neonatologia, cuidados de enfermagem, infant, newborn, neonate, congenital heart defects, heart abnormalities, malformation of heart, neonatal intensive care units, nursing care.

In the selection of the literature, we applied the following inclusion criteria: articles with complete texts available, published in Portuguese and English, addressing questions related to the topic or answering the research guiding question, and articles involving the participation of nurses. It was important to include studies carried out after February 2004 due to the publication of Ministerial Order No. 198 of the Ministry of Health, which established the National Policy of Permanent Education in Health as a strategy of the Unified Public Health System for the training and development of workers for the Sector[10].

The exclusion criteria were as follows: unavailability of full texts, letter-response studies, editorials, review-method studies, narrative reviews, traditional literature reviews, case studies, primary studies that did not address the topic, articles with no participation of nurses in the research, and those published before February 2004. Duplicated studies were also excluded in the selection of articles. To make the selection, we read the articles' titles and abstracts, as well as some complete texts, in order to determine whether they covered the research question and met the inclusion or exclusion criteria. The search resulted in 470 eligible studies. After the first reading and application of the inclusion and exclusion criteria, 25 studies were selected. After the second reading, however, only nine were selected as the final sample of the review. Of the total search, 57 studies were not related to the theme, three were editorials, nine were repeated in the databases, 341 had no complete texts available, in three there was no participation of nurses in the research, 31 were out of the timeframe, five were letters to the editor, seven were review studies, four were case studies, and one was published in Spanish. The first three steps of the review are summarized in Figure 1.

Data extraction and analysis were carried out through an adapted instrument that addressed the identification of the article and its authors, year and country of publication, study institution, publication journal and methodological characteristics of the study (type of research, its question or goal, sample, data treatment, interventions performed, results, analysis, implications/conclusions, authors' recommendations and evidence level), and also method precision evaluation. The information was analyzed and synthesized in thematic categories through the approximation of similar themes addressed in the studies. The results were presented in tables with titles, authors, journals and year of publications, sources (databases), goals, sample and methodological details, results, conclusions, types of clinical questions of the studies and their respective levels of evidence, according to the classification proposed by Melnyk and Fineout-Overholt[6].

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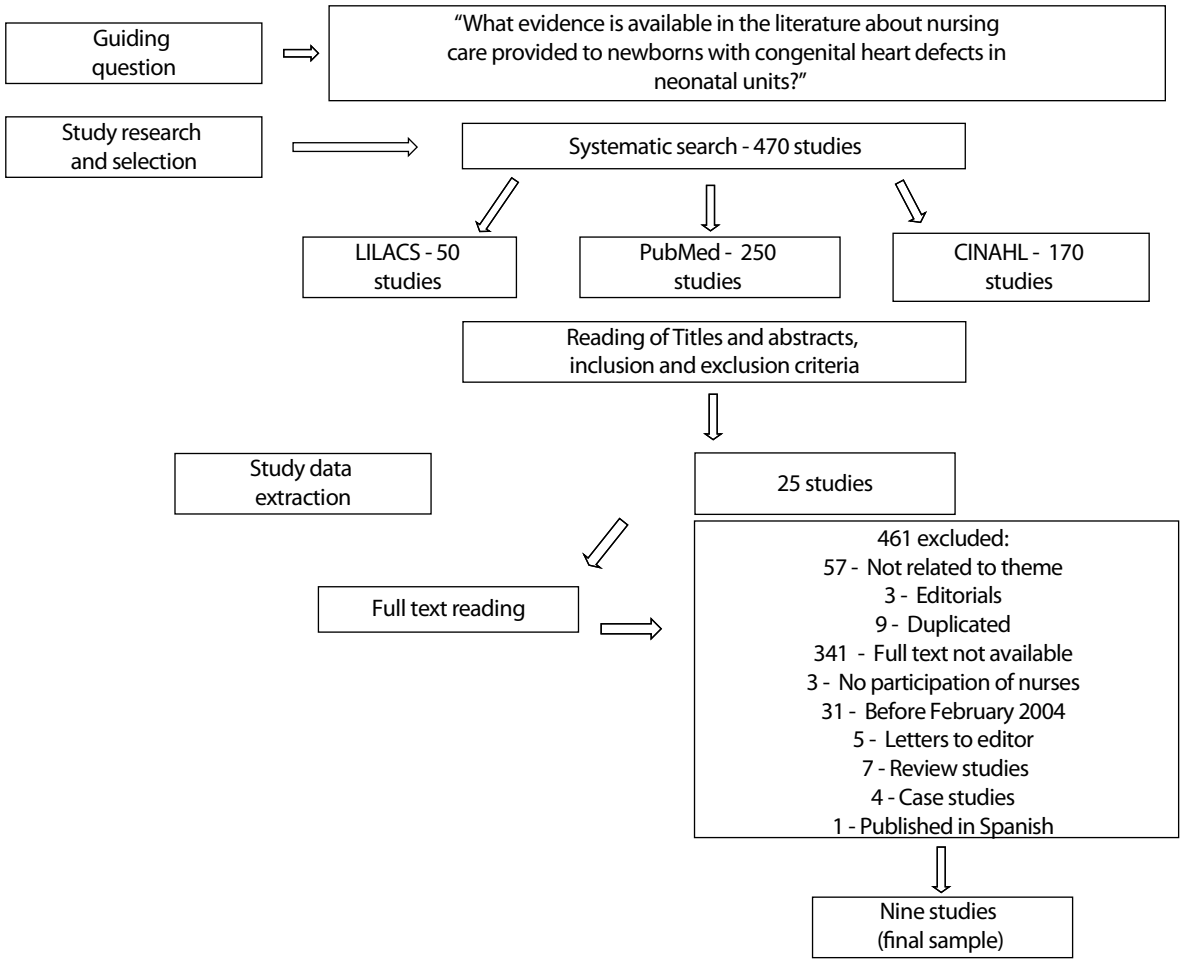
Figure 1 - Summary of the first three stages of the integrative review about care for infants with congenital heart defects in neonatal units. Fortaleza, 2015. Source: author's research



RESULTS

Of the nine studies selected, we found one dissertation which, despite being considered gray literature, was relevant to the topic and not determined as subject to the exclusion criterion. As for the language of the publications, four were in the English language and the remainder in Portuguese. Only one article was selected from the CINAHL database and two from PubMed. The others were selected from LILACS. In addition to the dissertation, the studies in the final sample were published in seven different journals, two of which were aimed at the medical public. The years with the greatest number of publications were 2012 and 2014. With regard to the clinical subjects of the studies, three spoke about intervention/treatment or diagnosis/diagnostic tests, having different evidence levels (III, IV and VII). Two addressed issues of meaning, both with level IV of evidence. The remaining studies (four) dealt with questions about prognosis/prediction or etiology, all of which were classified as level IV evidence. Three studies specifically discussed congenital heart disease. The others presented care measures pertinent to neonates and their relatives, which also apply to babies with heart diseases, so they were considered in this review. Thus, the studies were arranged in three categories, as follows: A) Recognizing congenital heart disease, with two studies; B) Providing care to the neonate in the intensive care unit, with four

studies; C) The family and the care measures to the newborn, with the remaining three articles. Figure 2 below shows the main characteristics of the studies:

In the selected studies, the best level of evidence was level III, related to the intervention/treatment or diagnosis/diagnostic test research question, which was a quasi-experiment. This study was published in a medical journal, with the participation of physicians of various specialties (cardiovascular surgeons, pediatric cardiologist, anesthesiologist and resident physician) and a nurse (instrumentation). Among the national studies, three were developed in the state of Ceará and published by nurses in that state. The others were published by nurses from the South and Southeast of Brazil. Among the selected studies, the main results specifically related to congenital heart diseases were the heart test (neonatal screening for critical congenital heart diseases), the identification of signs and symptoms, as well as assistance in the exams and surgical procedures to which the babies were submitted. Almost all of these were descriptive studies, but they provoked reflection on the care given to babies with heart diseases.

DISCUSSION

Congenital heart disease is present from birth, but may not be detected immediately. Therefore, its recognition is a fundamental step in proper care. In most services, neonatal screening for critical congenital heart defects is a nursing activity, but we could not find any studies in the research carried out by nurses directly dealing with the care provided in this practice. Perhaps this was because it is a relatively new activity, since it was not until 2014 that the "Heart Test"

Figure 2 - Main characteristics of selected studies as final sample of the integrative review. Fortaleza, 2015. Source: author's research

Category	Aim	Methodological Mapping	Results
A(11)	To develop strategies for the implementation of safe, effective and efficient screening.	Qualitative-descriptive study	-Definition of the sample and screening goals, technology (pulse oximetry) and criteria (algorithm); Diagnostic strategies (echocardiogram, chest x-ray) -Connection with home care / primary care -The role of public health and the providers of family care and education in the process -Coordination of the implementation of activities
A(12)	To describe the clinical characteristics of terms found in nursing records in the charts of children with congenital heart disease	Observational cross-sectional study (according to the authors)	-The average age of the children was eight months, with 8.5% of the total being neonates -53.7% of the children were admitted to surgery and 58.5% had cyanogenic heart disease, mainly tetralogy of Fallot. - The most frequent disease among children was ventricular septal defect -19.5% of the cases were associated with Down syndrome -The terms found in the medical records were: cyanotic, respiratory effort, tachypnea, pale, tachycardia and fatigue when suckling

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B(13)	To describe the interaction between nurse and neonate during the practice of providing care in processes of orotracheal aspiration and collection of blood for exams, with emphasis on the physiological and behavioral responses	Exploratory-descriptive research, qualitative approach (authors)	-Increased heart rate and decreased oxygen saturation -I-This Relationships characterized by the technical touch of the nurses -I-You Relationships were not continuous attitudes -Relations may suffer influences from the environment, emotional and psychological state of the subjects of the relationship -The caring touch could not be achieved
B(14)	To know the nursing care measures provided in the prevention of skin lesion in neonates	Exploratory-descriptive study, with qualitative approach	-All the nurses demonstrated knowledge about the skin characteristics of preterm infants, as well as sensitivity and professional experience - Care measures in the prevention of injury: use of hydrocolloids in bony prominences, daily hygiene, use of transparent film as protection, barrier to fix electrodes, removal of adhesives with the use of mineral oil, skin evaluation, change of decubitus and small use of adhesives -Factors for prevention: monitoring, hygiene, change of decubitus and adequate perfusion
B(15)	To prove the effectiveness of surgical intervention at bedside in the ICU, preferable for premature babies with persistent ductus arteriosus	Quasi-experiment with two groups (> 1000g and <1000g)	-Weight at birth, gestational age and weight at the time of surgery were significantly different between the groups ($p < 0.05$) -Maternal status, postoperative day of surgery, discharge day and number of pregnancies were not significantly different -There were no surgery or hospital mortality -The time for surgical indication is controversial, but the procedure is effective
B(16)	To evaluate the prevalence of neonates with congenital malformations in public institutions and the nursing care practice during the first 24 hours of infants' life	Descriptive, cross-sectional and quantitative study (author) in three institutions	- The mean prevalence of malformations was 3.0% -The most relevant malformations were hydrocephalus, myelomeningocele, anencephaly, congenital crooked foot, polydactyly, and upper and lower limb deformity - Congenital heart disease accounted for 10% of the sample - Therapy in the first 24 hours: oxygen therapy and maintenance of the airways, nutrition, drug therapy, installation of venous access, water balance, assistance in surgical procedures, dressings, hygiene and comfort and orientation to parents
C(17)	To know the experience of the relatives of children hospitalized in a neonatal intensive care unit (NICU) to obtain subsidies to improve patient and family care practices	Exploratory-descriptive study, qualitative research (authors)	- Central category of the study was "experiencing the hospitalization of the neonate in NICU" -Other categories: definition of the NICU; Reasons for hospitalization; Information received; Reaction of family members; Meaning of having a child hospitalized in the NICU; Feelings generated; Assessment of care measures; Participation of family members in care practice; Involvement in care practice; Evaluation of the assistance received -Family members show fear, but get engaged with the care practice and evaluate it positively -Family mostly remembers the doctor and social worker as the caregivers

C(18)	To investigate which interventions related to the nursing diagnosis "conflicts in the roles of father/mother" were recognized by the mothers of premature infants hospitalized, as the support to the maternal role	Cross-sectional and descriptive study (authors)	- Civil status, education level, number of pregnancies, complexity of care measures (intensive or semi-intensive) and gestational age were not significantly associated with the nursing diagnosis in question - Main activities considered important by mothers: talking with the mother about the baby's temperament characteristics; Offering the mother the opportunity to hold and care for the baby; Promoting maternal participation in decisions about care practice, generating trust in the team; Informing the mother about the care measures and equipment used; guiding the mother about her responsibility regarding the needs of the children and the resolution of their problems; Listening to mothers respecting concerns, feelings and doubts; Offer joint accommodation; Encouraging the mother to participate in support groups and to help her identify the maternal role.
C(19)	To identify the perception on neonatal nursing in mothers and / or fathers of neonates in intensive care	Descriptive study of qualitative approach (authors)	- Nursing as substitute for doctor srefers to the humanized care - Nursing as substitute of the maternal figure provides parents with sense of security - Negative feelings associated with hospitalization (fear of death) -Highlighted the behavioral skills and attitudes that differentiate competent assistance

was instituted as part of the Brazilian neonatal screening program.

The review selected a study that outlined strategies used to establish pulse oximetry as a screening program for critical congenital heart diseases[11]. Screening for pulse oximetry is an effective process that can increase the early detection of the seven major cardiac defects and is a painless and non-invasive technique to measure pre and post ductal oxygen saturation in newborns. This screening may help to identify hypoxia not detected by the human eye, being a simple and economical tool that complements the clinical evaluation[20]. Currently, nurses are directly involved in this type of screening, and can develop it in health services. Hence, the importance of being aware of studies that approach this activity as an important field of action of neonatal nursing. They need, therefore, to have an understanding of the development of the activity and skills involved in its execution, as described in the study, which brings scientific evidence to support the care practice.

The review also selected a study with charts of children, in which the nurses registered the clinical characteristics of the babies with congenital heart diseases. These are all important signs for the recognition of the problem and a correct evaluation and planning of the assistance provided. However, the characteristics related to the emotional, social and/or spiritual aspects of the family were not recorded and these characteristics are also important in order to plan appropriate care measures[12]. This study presented nursing records that demonstrated the signs and symptoms of congenital heart disease, but were not specific for neonatal nursing, the focus of the study. However, the research recommended family-centered care, in addition to aspects that transcend the biological, which is so important in the context of child health care.

The hospitalization of a child with congenital heart disease, especially for surgery,

represents a crisis for the family system, with a mixture of feelings (fear of death, surgery, anesthesia, guilt, impotence) throughout the disease process, but it also represents a perspective of healing and improvement in the quality of life[21]. Three of the four studies grouped in the neonatal care category in the neonatal unit did not specifically address the provision of care to newborns with congenital heart disease, but were also included as evidence about the provision of care for these children. The first study, synthesized here, demonstrated the need to work with the understanding of the "newborn being", which was based on the Humanistic Theory, to evaluate the relationship of care practices in neonatal intensive care, specifically invasive procedures. It was concluded that it is possible to establish a true encounter, although the researchers did not observe this relationship at the time of the care practice during monitoring in the field of research[13]. This situation also highlights the need to expand nursing clinical competence, which involves the ability and attitude to treat a specific population, such as newborns with congenital heart defects. This involves a whole structure, including the family, in an intense way, and demands from the professional an even closer approach to the patient, in a humanized relationship. In this approach, it is necessary to involve the family in the process of providing care to the child, which modifies the relationship of the professionals with the parents and changes the quality of the service, changing the whole dynamics of work. The transformative professional action begins by considering, a priori, that the family is the owner of specific knowledge, and of a world view, constituted by its praxis, in common sense, that must be valued, considered and respected[22].

The study that discussed the prevention of skin lesions on the baby emphasized the importance of skin care for the integral care of the newborn, including those with congenital heart diseases, emphasizing the qualification and sensitivity of the health care professionals, acquired through experiences and continuing education in service[14]. Prematurity often occurs with congenital heart disease. Premature babies have even more fragile skin than full-term babies, which can be the gateway to infections. For babies with heart disease infection is already a major risk, which is exacerbated in the case of preterm births and low birth weight. Thus, taking care of patients' skin with the best possible evidence is an important measure for this population.

The study that reported on the arterial canal ligation at the bedside, despite the publication in a medical journal, denoted the important presence of the nurse in the composition of the team that performs the procedure. Research has proven that the technique minimizes the risks to which babies may be exposed in the case of a surgical intervention outside the neonatal unit - transportation, hypothermia, handling, among others[15]. Early prophylactic surgery is considered to reduce the fatal complications of prematurity, such as necrotizing enterocolitis and bronchopulmonary dysplasia[23]. Thus, providing assistance to babies submitted to arterial canal ligation is also neonatal nursing care, even in a maternity ward, without specialized cardiology and/or surgery services.

Like congenital heart disease, other malformations are constant in the reality of neonatal units. The dissertation that was part of the sample of this integrative review, which addressed the care delivered to babies with congenital malformations, also addressed babies with cardiac defects. The results of the study showed that most of the care measures for infants with congenital malformations during their first 24 hours of life referred to exams and surgeries, which confirms the approach of the study cited

above. The author emphasized the need for scientific knowledge as an essential condition for nurses to promote health care, as well as to stabilize their patients' clinical condition, solve problems and improve the prognosis of these children in their future life[16]. Essential nursing competencies should be determined based on patient and family needs, reflecting a dynamic integration of knowledge, skills, experience and attitudes to identify these needs and optimize the results[24].

Nurses who work in neonatology need to be able to provide care to babies with conditions, because extra-cardiac abnormalities, including those which are abdominal, are often associated with congenital heart diseases. Babies with these abnormalities may present a higher risk of morbidity and mortality[25]. The dissertation on malformations also highlighted family-centered care, an aspect that cannot be dissociated from quality nursing care intended for infants with malformations[16]. As the search carried out found studies that addressed this aspect of professional care, they were grouped in the category "The family and the provision of care to the newborn", demonstrating their importance.

The first study analyzed in this category reported the experience of families of children hospitalized in a NICU. It did not specifically address infants hospitalized for congenital heart disease, but the feelings experienced can be extended to families in this population. The experience described was marked by feelings of fear, uncertainty and tension that can affect the family structure as a unit of care practices. Thus, the study emphasized the need and importance of involving the family in care and that the family, itself, should also be the object of nursing care[17].

In the same context, another study addressed the opinions of the mothers of the hospitalized babies, about what they perceived about nursing interventions. Using the Nursing Intervention Classification (NIC), classification for a nursing diagnosis, of the North American Nursing Diagnoses Association (NANDA International), the study showed that nursing actions should seek to support mothers in the neonatal unit to establish a relationship of trust and better development of the maternal role. It also demonstrated that the implementation of these actions does not require greater technology, besides the professional and human ability to provide care for women who make up the mother-child binomial[18].

Finally, the last study described the viewpoint of the families with infants hospitalized at the neonatal unit, about the nursing care performed. There was an understanding of the importance of such care measures and the recognition of their humanization, but there was still a limitation to the comprehension of the breadth of the actions of these professionals by the families, basically restricting them to technical, procedural measures[19].

CONCLUSION

The search for evidence through the identification, gathering and synthesis of knowledge, the objective of this study, showed that there is little evidence available in the literature dealing with the theme of nursing care measures to the baby with congenital heart disease, within the scope of a neonatal unit. In many of the studies reviewed, the nurses dealt with postoperative care in specialized units, rather than in the maternity units where the babies often stayed until a specific intervention was performed.

The review study demonstrated the need for greater involvement of nurses to improve the nursing care for children with congenital heart defects. It also highlighted that there are gaps in nurses' knowledge production that

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supported the need for improvement, in order to implement evidence-based clinical practice. We consider that the path to the improvement of care is always through science, with the development of studies that will strengthen this care, integrating theory and practice.

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