



# The transition of breastfeeding children with cleft palate and lip among women

## *A transição na amamentação de crianças com fenda labial e palatina* *La transición en la lactancia materna con hendidura labial y palatina*

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### ABSTRACT

**Objective:** To discuss the maternal transition in the breastfeeding process of children with cleft lip and palate, from the perspective of the transition theory. **Method:** Qualitative research of the case study type. The semi-structured interview was used as a data collection instrument. The results were analyzed from the Transition Theory. **Results:** The participant presented the transitions: situational, developmental and health-illness due to the change of social roles, the need to care for the child with malformation and the changes in her life due to her child's illness. It was identified, in the participant, the difficulty of exercising maternal breastfeeding care, interfering in its developmental and situational transition. **Conclusion and implications for practice:** The transitions were ineffective in taking into account the transitions covered. The presence of a nursing professional in the evaluation, follow-up and supplementation of the mother in the suckling of children with cleft lip and palate is essential to achieve the healthy transition.

**Keywords:** Cleft Lip; Nursing Theory; Breast Feeding; Nursing; Congenital Abnormalities.

### RESUMO

**Objetivo:** Discutir a transição materna no processo de amamentação da criança com fenda labiopalatal, na perspectiva da teoria da transição. **Método:** Pesquisa qualitativa do tipo estudo de caso. Utilizou-se, como instrumento de coleta de dados, a entrevista semiestruturada. Os resultados foram analisados a partir da Teoria da Transição. **Resultados:** A participante apresentou as transições: situacional, desenvolvimental e saúde-doença devido à mudança de papéis sociais, à necessidade de cuidar do filho com malformação e às modificações em sua vida em função da doença do filho. Identificou-se, na participante, a dificuldade de exercer o cuidado materno de amamentar, interferindo na sua transição desenvolvimental e situacional. **Conclusão e implicações para a prática:** As transições foram ineficazes levando-se em consideração as transições percorridas. A presença de um profissional de enfermagem na avaliação, acompanhamento e suplementação da mãe na amamentação de filhos com fenda labiopalatal é imprescindível para o alcance da transição saudável.

**Palavras-chave:** Fenda Labial; Teoria de Enfermagem; Aleitamento Materno; Enfermagem; Anormalidades Congênitas.

### RESUMEN

**Objetivo:** Discutir la transición materna en el proceso de lactancia del niño con hendidura labial y palatina, en la perspectiva de la teoría de la transición. **Método:** Investigación cualitativa del tipo estudio de caso. Se utilizó, como instrumento de recolección de datos, la entrevista semiestructurada. Los resultados fueron analizados a partir de la Teoría de la Transición. **Resultados:** La participante presentó las transiciones: situacional, evolutiva y salud-enfermedad debido al cambio de roles sociales, a la necesidad de cuidar del hijo con malformación y las modificaciones en su vida en función de la enfermedad de su hijo. Se identificó, en la participante, la dificultad de ejercer el cuidado materno de amamentar, interfiriendo en su transición evolutiva y situacional. **Conclusión e implicaciones para la práctica:** Las transiciones resultaron ineficaces teniendo en cuenta las transiciones recorridas. La presencia de un profesional de enfermería en la evaluación, acompañamiento y suplementación de la madre en la lactancia de hijos con hendidura labiopalatal es imprescindible para lograr la transición sana.

**Palabras clave:** Labio Leporino; Teoría de Enfermería; Lactancia Materna; enfermería; Anomalías Congénitas.

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Submitted on 05/21/2018.

Accepted on 10/02/2018.

DOI: 10.1590/2177-9465-EAN-2018-0152

## INTRODUCTION

The maternal milk constitutes one of the food offered after birth, having as one of the vehicles the breastfeeding. The maternal milk offered in the breastfeeding contains micronutrients responsible for growth and development of the child, as well as bioactive compounds like oligosaccharides, proteins, peptides that actuate on the protection of children against infections.<sup>1</sup>

Breastfeeding is the process for which suckling her child takes place by direct suckling foster mother, being the most effectively manner of meeting the nutritional and immunological aspects, offered by the maternal milk.<sup>2</sup> The performance of the breastfeeding extends to psychological level and involves deep interaction and the building of the child mother relationship the best mother and child.<sup>3-5</sup>

This breastfeeding process becomes impaired in children with cleft lip and/or palate (CLP) due to anatomical structures of the face, which interferes with sucking and swallowing.<sup>3-6</sup> As such, the assistance to children with CLP is one of the main global problems in public health and affects one in 500-1000 births and is the craniofacial abnormality more commonly found. It represents a quantitative of 240 thousand children per year<sup>7</sup> and result from fusion defects of the craniofacial processes that occurs between the fourth and the twelfth week of pregnancy.<sup>2,3,8,9</sup>

A child diagnosed with CLP precipitates the need of changes and adaptations and triggers the transition, process constituted by a movement for adaptation to change, in the person's life after an instable period, given the occurrence of a disturbance. Individuals affected by the CLP and their families suffer a great impact in the life quality and psychosocial wellbeing, as this alteration could lead to repercussions on speech, respiration, feed and dental problems.<sup>8-11</sup>

Given the complex context which involves the care for the child with CLP and, specially, the breastfeeding process, it proposes to discuss the maternal transition in the process of breastfeeding child with cleft lip and/or palate, in view of the transition theory.

## THEORETICAL REFERENCE

The present study anchors itself in view of Afaf Ibraim Meleis's theory of transitions, subsidizing the work nurse on understanding the transitions occurred with mothers of children with CLP, stimulating these women's empowerment and autonomy during the breastfeeding process.

The Theory of transition proposes a systematized assistance facing the pluralities of transitions and precipitator factors such as the CLP. It has as axes and interfering factors in this process, the nature of the transition (Type, Standard and Properties), facilitator and inhibiting conditions (Personal, Community, Society) and patterns of response (process indicators and outcome indicators) and the nursing therapy.<sup>11-13</sup>

The nature of the transitions refers to the transitions profile and classifies in four types: developmental, situational, health disease and organizational. The developmental refers to situations of the life cycle. The situational occurs when there is change in roles of an individual in its family or society and the health disease when a disease affects the individual. Finally, the organizational type occurs when socio-economic and political factors influence the individual life.<sup>11</sup>

The types of transitions manifest themselves meeting patterns divided into number of transitions, organization and the possible relationships existing among them. With regard to the number of transitions, they can be simple, where the individual passes through an isolated type of transition or multiple, when several types of transition occur in the same time space. When the individual has the need of more than a transitional event, they organize simultaneously, where they perform simultaneously or sequentially when they manifest and grow on cascade effect. Causal relationship can or not exist among the transitions type, and can be classified into related or not related.<sup>11</sup>

The transition properties constitute a dynamic and associated process, and characterize by awareness, involvement, change and difference, and time space and critical events. The awareness relates to the perception, knowledge and recognizing of living the transition process and the involvement corresponds to the degree of interaction in the face of the lived situation.<sup>11</sup>

The change refers itself to events of imbalance in the relationships, routines and ideas. The difference, however, treats of the behavioral alteration, with the satisfaction or divergence of expectations. The time space characterizes by the period necessary to experiment different strategies and incorporate them in its own knowledge. However, the critical events summarizes in situations of highlighted situations within the transition process.<sup>11</sup>

The second axis of the transition, called as facilitator or inhibitor of transition, can be personal, community and social. There are four personal conditions where the meaning corresponds to the representability of the lived situation and the preparation and Knowledge, which are associated with the knowledge about intelligible expectancies and strategies in the transition process.<sup>11</sup>

The third personal condition, socio-economic occurs when the work and the income generation influences the health situations, and the fourth are cultural beliefs and attitudes that influence the individual who live the transition.<sup>11</sup>

The community resources are also conditions for the transition and include the support for the community group, support for the health professionals and clarification of questions. Another interfering factor of the transitional process of the individuals is the society, which includes the institutions and organizations, with structural, solidary and creative processes categories.<sup>11,14</sup>

The third evaluative axis of the transition theory is entitled pattern of responses and mark out the condition of the transition

and of possible risk situations and vulnerability during the process of change. It divides into process indicators and outcome indicators. As process indicator it has been: feeling connected, interacting, location/being situated and developing confidence and coping.<sup>11</sup>

Feeling connected treats of the social network that the individual establish with friends, family and with health professionals and the interaction refers to the discovering problems and subsequent - related clarifications and the strategy development. The location refers to senses and perceptions attributed to the individual's experiences in the transitional process, resulting from the individual's displacement from one place to another.<sup>11</sup>

Developing confidence and coping relates to the way that the individual deals with changes, such as the diagnosis, therapeutic possibilities, limitations, available resources and the strategies adopted.<sup>11</sup>

In the outcomes indicators it evaluates the mastery while individual competences during the transition process and the fluid integrative identity refers to the changes in the identity or -related conditions in the transition process.<sup>11</sup>

After the raising of these elements, it has been the nursing therapeutic, carried out through the nursing supplementation that aims supply the client's hyposufficiency in its specific transitional needs. The result of these transitions can be: healthy, ineffective or insufficient role. It is healthy when the individual has the domain of knowledge. It is ineffective, when there are no ideary results and the individual is at risk situation and vulnerability. And with insufficient role, when there is some difficulty in playing a role.<sup>11,13</sup>

## **METHOD**

It's a descriptive, qualitative research, single- case study, carried out with a CLP child's. According to Hyett, Kenny and Dickson-Swift the case study is considered an approach used in qualitative research, that contain study designs and differentiated methods.<sup>15</sup>

According to Stake,<sup>16</sup> the process for developing the case study has 5 steps that are the suitability of the case study approach to embody the research problem, the selection of the case study, the data collection, type of analysis and the case data interpretation. The suitability of the case study for a problem to be investigated shall be carried out from the detailed delimitation of the research questions, in which it has an identifiable case with obstacles and seeks to understand them.<sup>16</sup> It verified the pertinence of adopting the single case study, which according to Stake<sup>16</sup> searches for understanding of a particular phenomenon, which, in this case, is the transition of the woman in the breastfeeding with CLP child.

The case study selection envisages a reflection, which will enable us to understand the phenomenon to be studied and the most appropriate type of the case study. We have opted for a single case study in order to facilitate the contextualization of the maternal transition in the face of the problems lived with the child with malformation.<sup>16</sup> The inclusion criteria for the selection

of the participant in the research was having CLP child under assistance in the referred center of treatment where they tried to begin the breastfeeding practice. The exclusion criterion adopted was presence of maternal mental disorientation that could make the case report inviable.

In the data collection a semistructured routing applied in interview was used a the tool, consisting of the following data: types of malformation, diagnosis, discovery of the malformation and orientations by the health professional; breastfeeding process (doubts, difficulties, effectiveness of the prostheses in the breastfeeding); orientations about the prenatal and postnatal about breastfeeding. The interview was recorded in MP4 and transcribed. It carried out consultations in the patient's medical records, using the same routing as guiding for data collection.

The type of analysis was carried out according to take delimitation<sup>16</sup> that proposes the detail of the case history, narrated by the interviewee from the prenatal to the repairing surgical procedure of the CLP of her child, being these data complemented with information from the patient's medical records.

The case data interpretation was implemented through the data organization and categorization in order to facilitate the problems delimitation.<sup>16,17</sup> After the fluctuating reading of the interview and of the medical records data, the same were grouped for similarity and organized in 1 thematic category: The mother's transitions with her child with CLP and the breastfeeding with 4 subcategories, which supported the axes of the Theory of Transition: Nature of the transition, Facilitator or inhibitor conditions of the transition process, Pattern of responses to transitions and Nursing Therapeutic.

The data were collected in July 2015, in a Center of Treatment of Craniofacial Abnormalities, in the Southeast of the country. The data collection occurred after the agreeing of the interviewee and respective consent, according the resolution no. 466/12 and approval by the Research Ethics Committee in the protocol no. 41/13 of the Secretaria Municipal de Saúde do Rio de Janeiro.

## **RESULTS**

### **The case report**

It is a mother of child with CLP, 33 years of age, home life, Catholic religion, married, completed high school, live in a municipality of the Southeast Region of the Brazil. Received the diagnosis of bilateral cleft-lip and palate of her child in the fifth month of pregnancy, after the carried out of the morphological ultrasound. Still during the pregnancy, the participant searched complementary information about the healthcare and the procedures adopted for the treatment of her child. The physician, in making the ultrasound examination, told the diagnosis to the pregnant woman, but the explanation about the fetal framework was provided in consultation by the pediatrician and the obstetrician that performed the follow-up in the prenatal. In addition to the orientations received, the participant searched in the internet information about the etiology and treatment for the facial abnormality. She received previous orientation by the health professionals regarding the procedures to be adopted after

the birth. She was unaware of the treatment for the abnormality correction. The birth was normal and the hospitalization period in neonatal unit was postponed for 2 weeks due to the diagnosis and wait period for the making of the palatal prosthesis. The professionals of the hospital did not orientate her appropriately regarding the breastfeeding process. And, also, her stay into the hospital was not allowed, in the rooming-in, during the hospitalization period of her child, in order to enable this process. One attempt to place the baby to suck was made, before the discharge, with milk output through airways. After this, she could not perform the breastfeeding, which led her to the mechanical milking practice and supply the milk through a small bottle. After making of the palatal plate, the neonate was discharged, and the mother was oriented about its handling. The breastfeeding complemented with artificial milk lasted until the 5<sup>th</sup> month, followed only by artificial milk. The reconstructive surgeries of the CLP, cheiloplasty and palatoplasty were carried out, with one year and 6 months.

## DISCUSSION

### The transitions of the mother with child with CLP and the breastfeeding

#### Nature of the transition

The maternity is one of the most common precipitator factors for the process of transition of a woman and is affected directly by the health conditions of her procreation.<sup>13</sup> The diagnosis of a child with CLP brings itself adaptation needs and the maternal challenge to care and exercise the maternity.

From the view of the theory of transition, about the nature of the same, the study participant in having a child with CLP presented two transitions: developmental and situational. The transition of the developmental type related to the change expected in the life cycle, as the maternity and the arrival of a child, that cause change in the pregnant and puerperal cycle of the woman and the completion of a socially expected phase of her life.<sup>11,12</sup>

The situational transition occurred with the arrival of more one individual in the family home, that altered the family structure, specially, with the arrival of an individual with craniofacial abnormality, with the need of the manufacture of the palatal plate and hospitalization, which caused the maternal roles redefinition.

The transitions presented multiple patterns, which occurred in a simultaneous and related way, common fact in the maternal transitions, as awake to the need of a series of transformations.<sup>11,12</sup>

The property of conscience for the transition occurred with the diagnosis in the prenatal with the information of the problem on the fetal formation, and of the needs after birth, complemented with the property of the maternal involvement, in front of the searching for information in means of communication, with friends and health professionals about the pathology and treatment of her child. It also showed itself present in the postpartum, through the expression of interest to breastfeed.<sup>11</sup>

The property of change had the CLP diagnosis as event of imbalance, in front of the pregnancy natural process, which interfered in the maternal dynamics. In the property of the difference it observes the non-attendance of the expectation of breastfeeding based on the needs of special healthcare so that the breastfeeding could occur successfully.<sup>11,18,19</sup>

The time space for the maternal transition initiated in the diagnosis and, taking into account the breastfeeding process unsuccessful, ended with the promotion of the exclusive artificial milk.

The critical events that marked the transition process<sup>11,18</sup> were the CLP diagnosis, the birth of the baby with abnormality, the desire to breastfeed the child and the difficulties/disabilities to do so.

### Facilitator or inhibitor conditions of the transition process

With regard to the personal conditions of transition it can be asserted that the meaning was an inhibitor condition of the transition, since includes the social imaginary of prejudice and discrimination to the child with disability and to the impossibility of the breastfeeding. The maternal adaptation to the condition of the child with CLP resulted in a new significance of possibilities for the being mother.<sup>11-13</sup>

The preparation and the knowledge have shown facilitator and inhibitor personal conditions. Facilitator for searching information about CLP and the interest of acquire knowledge so that the mother give care of her child. However, even the mother has interest in acquiring knowledge about the CLP and understanding the possible difficulties that would face, it was not enough to present a healthy transition in relation to the breastfeeding of her child, which characterizes as an inhibitor factor of the transition.

The socioeconomic level was not facilitator, nor inhibitor, which remains neutral in the transitional process, since the necessary tool for the breastfeeding practice was provided by the health unit and did not depend on the maternal financial resources.

The breastfeeding is a practice that brings with it beliefs and values socially constructed and transferred to each generation, complex to define patterns by the health professionals.<sup>19,20</sup> In the case study, the cultural beliefs and attitudes were personal conditions facilitator in the accreditation of the successful breastfeeding practice, which culminated in the attempt in the puerperium.

The community has proven a facilitator condition, with partnership and solidarity of the partner in the coping situations in front of a child with CLP. Studies indicate that the family represents the most important communitarian group for women in the developmental transition of the maternity.<sup>20</sup>

The health professionals carried out the encouragement of the breastfeeding and the lactation practice to the participant as an encouraging act for the carrying out of such practices, even without follow up and technical support. In this sense, the nurse,

as a health professional is considered as source of communitarian support and is fundamental to offer the most effective nursing supplementation, such as, in realizing the breastfeeding practice, "in the neonatal weight gain and in facilitating appropriate services"<sup>20,21</sup>

The society here represented, by the institutions that welcomed the woman with the child with CLP in the pregnancy and in the puerperium should provide emotional support, orient and clarify the mothers who recently gave birth about doubts regarding the neonate feeding, which has not been facilitated. In order to do so, the institutions shall have a well trained interdisciplinary team,<sup>4,22</sup> mainly, the nurse, as she is the responsible, in the majority of cases, by the follow up in the rooming-in 24 hours a day and in the basic attention.<sup>11,23</sup>

### **Patterns of responses to transitions**

Feeling connected to its social network showed a strong maternal connection with her child, followed by connection to the partner and the health professionals, although the latter has not reached the genuine function of this connection, of clarifying the inquietudes about the breastfeeding.<sup>11</sup>

The development of strategies in the step of interaction in the transition process occurred in a weakened way, in the face of the inexistence of knowledge exchange, without including empowerment actions of the participant about the breastfeeding of her child with CLP.<sup>4</sup>

The location generated interference in the transitional process, while senses and perceptions, in the face of the natural planning of displacement from the hospital unit to the domicile.<sup>11,18</sup> Through the birth of a child with special healthcare needs, there was the referral to Center of treatment of craniofacial abnormalities and to pediatric hospital to carry out the surgery, causing changes in terms of geographic location.<sup>13</sup>

The process of developing confidence and coping, in the sense of management of changes, occurred with the participant's previous preparation in accordance to the child's disease, diagnosis and treatment, which led to a deficit situation of coping and the desistance of this practice.<sup>11,18</sup>

The transitions theory describe two outcomes indicators, the mastery (competences) and a fluid integrative identity (construction of roles adapted to the transition need).<sup>11</sup> In this study, it clearly showed that there was no mastery for the breastfeeding effectuation, even though the mother had been seeking reformulations in the maternal identity to care for the CLP child.

### **Nursing Therapy**

About the nursing therapeutic, having in view the demands delimitation in light of the situational and developmental transition process presented by the participant in relation to her child with CLP, we observed the lack of a therapeutic that embraced the nursing care capable of enabling the mother's healthy transition process, mainly, in the performance of the breastfeeding. It is

necessary that the professionals develop competences and skills to carry out appropriate interventions and overcome the possible barriers, mainly, in the labor delivery room.<sup>24</sup>

The nursing therapeutic of effective incentive to breastfeeding should initiate in the prenatal, providing the orientations pertinent to the specific case that must continue in the post-natal, until the effectiveness of the breastfeeding practice.<sup>25</sup>

Initially, the nursing professional shall evaluate the viability of the breastfeeding and, therefore, understand the physical capacity of each child for the practice. Management protocols for breastfeeding of children with CLP show that it is possible this process, but that requires previous individual evaluation of the cases by the health professional and orientation and follow-up of the mothers, specially, of the nurse qualified to exert such practice.<sup>4,23,26,27</sup> There are no evidences that contraindicate the breastfeeding, on the contrary, constitutes a feasible nutrition method, although it is difficult.<sup>2,4,25</sup>

The breast milk feeding, indirect form of offering the mother's milk, either through a glass or through a spoon, must be provided before the attempt to introduce the artificial milk, which must be used as the last resource.<sup>2</sup> The mothers, in addition to the orientation, shall be advised about the possibilities of the breastfeeding is not the unique way of nutrition and the possible need of the supply on the mother's milk by other means.<sup>2,26</sup> In this case study, the artificial milk was prescribed, possibly, as a more practical mean of nutrition of the child with CLP.

Taking into account the mother's interest on the breastfeeding, the qualified technical support becomes fundamental to socialize the knowledge and the nurse is, including, referred as a qualified professional to drive such way. It emphasizes the importance of the orientation focused on the child's appropriate position during the breast-feedings, which must be in semi vertical or vertical position along with the mother's body, in order to minimize the risk of nasal regurgitation and the maternal milk reflux in the auditory tubes.<sup>2</sup>

In this case, the knowledge is essential for the breastfeeding process since it is necessary that the mother introduce as much the areola as possible inside the baby's oral cavity and that the lactiferous sinuses can be emptied with the sucking. During the sucking, the areola increases three times in length inside the baby's oral cavity, touching the hard palate and in a direction towards the soft palate, stimulating the sucking.<sup>3</sup> As the CLP exists, the pressure required in the areola for the milk ejection does not occur and strategies are needed for compensating this deficiency. In order to achieve appropriate sucking, it shall occur negative intraoral pressure. In children with CLP, the pressure is insufficient; consequently, the quantity and the flux of milk ingested are reduced.<sup>26,28,29</sup>

In this sense, the positioning of the nipple is essential for the breastfeeding success and must be placed in the most complete region of the palate or with the most intact bone in order to facilitate the nipple compression and prevent its insertion into the cleft. In case of bilateral cleft, the mother must project the nipple



towards the low region of the oral cavity and, if necessary, can also do the breast expression, as a substitute of the child's grabbing.<sup>2,4</sup>

The technological support, as the use of orthopedic prostheses, shall be used as a facilitator of the breastfeeding process, which shows be fundamental in the breastfeeding with the conduction of the maternal milk in the upper digestive track.<sup>2</sup> Despite the participant inform that there was available prosthesis for her child, in order to seal the palatal opening and enable the breastfeeding process, there was no good use.

Associated with the technical conduction, the monitoring and supervision of the actions referred in the breastfeeding should occur in order to guarantee the effective promotion of the breastfeeding.<sup>25</sup> The effectiveness of the breastfeeding shall be done through the observation of the sucking, of verifying the weight gain and hydration of the child with CLP. The insufficiency of positive data during the breastfeeding process can be an indicative of the need of the supplementary nutrition, with feed, but not a substitute.<sup>2</sup>

The therapeutic support shall be complemented through support groups of parents whose children have CLP and who have experienced the breastfeeding or feeding.<sup>2</sup> It is important to emphasize that the mother reported that the orientation process about the breastfeeding was stimulated in the puerperium, but not assisted, direct and continuously, by the nursing professional, nor there was redirection of the mother to support groups in the specialized centers of attention to children with CLP.

In this case study, the non-supplementation of role continued until the surgical repair of the CLP, with the carried out of the surgeries of cheiloplasty, for the lip correction, and palatorrathy, for correcting the palate, with 1 year and 6 months, that contradicts the protocols that recommend the nursing supplementation in the breastfeeding practice, since the birth.<sup>2</sup>

This way, ineffective transition occurred in relation to situational and developmental. The performance of the maternal role occurred partially before the establishing of the nutritional intake designed for her child.

## CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The objective of the study was reached with the discussion concerning the maternal transition in the breastfeeding process of children with cleft lip and palate, from the perspective of the transition theory. It showed that, through this diagnosis, the mother's feelings and reactions must be observed with care and attention. The difficulty in the face of the breastfeeding process stands out in front of a diagnosis, which was not expected and, neither, desired.

The moment of finding about the diagnosis also influences the process of understanding and accepting the situation. The presence of a nursing professional to clarify the family is essential so that the suffering in the face of the real baby can minimize

and the acceptance of the different child can occur naturally. In addition, this professional can help the family to meet the difficulties positively, and prepare the mother for breastfeeding process and help her to reach a healthy transition.

In this sense, the nurse's participation in the screening, reception and referral of the mother is fundamental, mainly to attend the need of efficient performance in the roles evaluation and supplementation in the transition process of women with CLP children. We considered, as a limitation of the study, the scarcity of records in the patients' medical records in order to complement the unknown technical information by the interviewee.

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