

# Transcultural Nursing Model Could Enhance to Quality of Life Thalassemia Patients

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## Transcultural Nursing Model Could Enhance to Quality of Life Thalassemia Patients

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**Abstract**—Thalassemia patient has physical and emotional problems due to illness condition, routine treatment, and it will affect their Quality of life. To relieve problems of the thalassemia patients, nurses should modify the environment of the patients and family by using the transcultural nursing model. **Methods:** It used a quasi-experimental method with pre and post-test design. There were 64 families of thalassemia patients who were participated as the sample by purposive non-random sampling technique and divided equally into the intervention and control group. The result showed that the mean post-test score of Quality of life in the intervention group was 118.22 (SD = 16.62). Meanwhile, the control group was 81.94 (SD = 12.26). There were significant differences in Quality of life among patients between the intervention and the control group ( $p = 0.001$ ). This research assessment focused on the cultural elements of Leninger's transcultural nursing. It is concerned with the cognitive ability to know about the values, beliefs, and expression patterns used to guide, support, or provide individuals, families, or groups with the opportunities to sustain health, be healthy, develop and survive. The conclusion is that the transcultural nursing model's application influences the Quality of life of thalassemia patients. It is recommended to nurses who care the thalassemia patients should apply the model of transcultural nursing.

**Keywords:** Quality of life, Thalassemia, Transcultural nursing

### Background

Thalassemia is a disease of blood disorders caused by a disruption of hemoglobin production, so hemoglobin decreases [1]. The incidence of thalassemia is also high in Southeast Asia [2]. Indonesia is one of the countries whose populations carry thalassemia. Thalassemia carriers in Indonesia is about 3-8%, and in some areas reach 10% [3]. One of the treatments of thalassemia is long-term transfusion, which affects physical functioning and creates psychosocial, emotional, social integrity, and school problems [4]. Research in Sanglah Bali Hospital proved that 37.5% of children with chronic thalassemia experienced behavioral problems; in addition, the clinical manifestations experienced by the children would affect their behaviors [5]. The treatment of thalassemia will also affect children and parents. Parents will be impacted in terms of the burden of time and energy to care for their children and to undergo treatment programs [6]. Meanwhile, the impact of continuous treatment programs over a long period of time on children is a decline in their Quality of life [7].

Quality of life consists of four dimensions of physical, social, role, and psychological [8]. A decline in the Quality of life in thalassemic children who are undergoing long-term treatment will have an effect on families who show sad, crying, and tense expressions. Such expressions will in turn, affect the children's conditions, especially their physical and psychosocial stability [9]. Research using the Pediatric Quality of life inventory (PedsQL) found that the negative impacts on physical, emotional, and school functions in children with beta-thalassemia major were worse than those in healthy children as the control [10]. On the other hand, research on families' responses to the physical, psychosocial, and emotional impacts of the declining Quality of life in children with thalassemia treated with transcultural nursing has not been carried out.

One of Leininger's transcultural nursing concepts is caring. Caring is the essence of nursing, which distinguishes, dominates, and unifies nursing actions. Culture is the result of human inventiveness,

taste, and intention in meeting the complex needs of life, including knowledge, belief, art, morals, customary law and skill, and habit [11]. Cultural elements are considered universal when found in all cultures across the world [12]. According to Koentjaraningrat, there are seven elements of universal culture, namely 1) Language, 2) Knowledge System, 3) Community System or Social Organization, 4) Life Tools and Technology System, 5) Livelihood System, 6) Religious System, and 7) Art. Herein, the research aims to examine the influence of the transcultural nursing model on the Quality of life in children with thalassemia at the Thalassemia Polyclinic of Dr. HasanSadikin General Hospital, Bandung.

#### Methods

The research is quasi-experimental, with the non-equivalent control group design. It involved a sample of 32 school-age children assigned to the control group and intervention group, respectively. The selection of sample was done purposively or non-randomly from the school-age children who were undergoing outpatient treatment at the Thalassemia Polyclinic at Dr. HasanSadikin General Hospital, Bandung from August to October 2016.

The research process began with the selection of samples according to the inclusion criteria. Then, the children were divided into 2 groups, namely the intervention group and the control group. Before the intervention, the researchers first measured the Quality of life of the children by asking the families to fill in the instrument of Pediatric Quality of Life Inventory (PedsQL), [14] covering five domains: a) health and physical activity (8 questions); b) emotional (5 questions); c) social relationships at home (5 questions); d) school (5 questions); and e) aspects related to their self-image (7 questions). Each question weighted 0 to 4, and the higher the score, the better the Quality of life. The score of each domain was calculated by multiplying the average of each component by 4. Subsequently, the intervention of nursing care with the transcultural nursing approach for 30 minutes in three patient visits to the polyclinic was carried out, followed by measuring the Quality of life of the children on the third visit. The media used in the transcultural nursing application consisted of a guideline of nursing care in thalassemic children with a transcultural nursing approach and a module on how to recognize and improve the Quality of life in children with thalassemia.

The data collected were then processed and analyzed with univariate, followed by bivariate analysis [15]. The univariate analysis involved frequency distribution in describing the categorization of each thalassemia and the Quality of life of the children using the central tendency of the mean value and dispersion of the minimum, maximum, and standard deviation to describe the value of the Quality of life of the children numerically.

Bivariate analysis was preceded by a data normality test using Shapiro Wilk. If the Quality of life of children's data is normally distributed, it will be tested using a parametric test, namely an independent *t*-test. On the other hand, if the data are not normally distributed, then to compare the mean difference between the intervention group and the control group, the Mann-Whitney test will be performed. The null hypothesis is rejected if the *p*-value <  $\alpha$ . ( $\alpha = 0.05$ ).

#### Result

Table 1. Distribution Characteristic of the Thalassemia Children's Parents in the Intervention and Control Groups

Categories	Groups
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	Intervention				Control			
	Average	Youngest	Oldest	SD	Average	Youngest	Oldest	SD
<b>Age</b>								
<b>Father</b>	40.19	27	62	7.09	39.5	28	50	5.98
<b>Mother</b>	36.47	25	50	6.1	35.5	25	48	6.03
<b>Education</b>	Frequency		%		Frequency		%	
<b>Father</b>								
Elementary	3		09.4		0		0	
Junior High	8		25.0		4		12.5	
Senior High	18		56.2		23		71.9	
University	3		09.4		5		15.6	
<b>Mother</b>								
Elementary	4		12.5		2		06.3	
Junior High	12		37.5		12		37.5	
Senior High	15		46.9		16		50.0	
University	1		03.1		2		06.3	
<b>Occupation</b>								
<b>Father</b>								
a. Civil Servant	0		0		1		03.1	
b. Trader	6		18.8		7		21.9	
c. Interpreneur	1		03.1		4		12.5	
d. Farmer	3		09.4		3		09.4	
e. Private Employee	20		62.5		14		43.8	
f. Service Industry	2		06.3		3		09.4	
<b>Mother</b>								
a. Civil Servant	1		03.1		1		03.1	
b. Trader	2		06.3		6		18.8	
c. Interpreneur	1		03.1		1		03.1	
d. Farmer	4		12.5		4		12.5	
e. Private Employee	7		21.9		7		21.9	
f. Housewife	17		53.1		13		40.6	

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Table 1 shows that the average age of fathers in the intervention group was 40.19, which is older than the mean age in the control group. The eldest in the intervention group was 62 years. Meanwhile, there was almost no difference in the mean age of the mothers in both the intervention group and the control group.

The education parents know that more than half of the fathers in the intervention group (56.20%) were senior high school-educated. In contrast, almost half of the mothers (46.90%) had senior high school education. In the control group, most fathers (71.90%) had high school education, and there was a

small portion (15.60%) with a university education, while half of the mothers (50%) were senior high school-educated.

The Occupation parents are found that most fathers in the intervention group (62.50%) worked in private companies, while more than half of the mothers (53.10%) were housewives. The control group (43.80%) worked in private companies, whereas almost half of the mothers (40.60%) were housewives.

Table 2. Frequency Distribution of Age Categories of the Thalassemic Children in the intervention and the Control Groups

Age Category	Groups			
	Intervention		Control	
	Frequency	%	Frequency	%
<b>Age</b>				
7- 9 year	16	50	10	31,3
10-12 year	16	50	22	68,7
<b>Total</b>	32	100	32	100

Table 2 indicates that in the intervention group, half of the children half (50%) were aged 7- 9 years, and the other half aged 10-12 years. In the Control Group, it is known that more than half of the children (68.70%) were included under the category of 10-12 years old.

Table 3. Distribution of Thalassemic Children's Ages in the Intervention and Control Groups

Group	Average	Youngest	Oldest	SD
Intervention	8.72	7	12	2.37
Control	9.78	7	12	2.36

Table 3 shows that the average age of children in the intervention group was 8.72, with the youngest being seven years old and the oldest 12 years old. Meanwhile, in the control group, the average age of children was 9.78, with the youngest age of 7 and the oldest 12.

Table 4. Frequency Distribution of the Quality of Life in the Thalassemic Children before and after the Implementation of Transcultural Nursing Model in the Intervention and Control Groups

Quality of Life in Children	Groups			
	Intervention		Control	
	Frequency	%	Frequency	%
<b>Before</b>				
a. Good	16	50	15	46,9
b. Average	16	50	17	53,1
Total	32	100,0	32	100
<b>After</b>				
a. Good	25	78,1	16	50,0
b. Average	7	21,9	16	50,0
Total	32	100,0	32	100

Based on data presented in Table 4, prior to the treatment of the transcultural nursing model to the intervention group, only half of the children respondents (50%) with thalassemia had a good quality

of life. Meanwhile, after the implementation of the transcultural nursing model, most children with thalassemia (78.1%) in the group had a good Quality of life. This shows an increase in the Quality of life before and after the treatment of thalassemia with the transcultural nursing model. In the control group without the treatment of transcultural nursing model, in the initial measurement, less than half of the children with thalassemia (46.9%) had a good quality of life. Meanwhile, in the final measurement, half of them (50.0%) had a good quality of life. This indicates that there was almost no change in the Quality of life in the children from the initial to the final measurement.

Table 5. Comparison of the Scores of Quality of Life in Children with Thalassemia before and after the Implementation of Transcultural Nursing in the Intervention and Control Groups

Quality of life in Children	Intervention					Control				
	Average	Lowest	Highest	SD	p-value	Average	Lowest	Highest	SD	p-value
Before	80.88	53	114	16.62	0.001	80.32	50	110	16.20	0.109
After	118.22	102	136	8.81		81.94	64	106	12.26	

Based on Table 5, In the Intervention group, the Quality of Life of the thalassemia children before the implementation of the transcultural nursing model was 80.88, with the lowest being 53, the highest 114, and with a standard deviation (sd) of 16.62. Meanwhile, after the transcultural nursing model's implementation, there was an increase in the average to 118.22, with the lowest value being 102, the highest 136, and a standard deviation of 8.81. A p-value of  $0.001 < \alpha (0.05)$  was reported; thus, the null hypothesis is rejected, which means there was a difference in the Quality of life in children with thalassemia before and after treatment with the transcultural nursing model. The Control Group shows the mean value of Quality of life in the control group thalassemia children in the before measurement was 80.32, with the lowest being 50, the highest 110, and a standard deviation of 16.20. There was almost no increase in the after measurement, in which the average slightly raised to 81.94, the lowest being 64, the highest 106, and with a standard deviation of 12.26. p-value of  $0.109 > \alpha (0.05)$  was obtained; hence, the null hypothesis is accepted, which means there was no difference in the Quality of life of thalassemia children in the control group between the before and after measurements.

Table 6. Comparison of the Scores of Quality of Life in Thalassemia Children in the Initial and Final Measurement between the Intervention and Control Groups

Groups	Initial					Final				
	Average	Lowest	Highest	SD	p-value	Average	Lowest	Highest	SD	p-value
Intervention	80.88	53	114	16.62	0.873	118.22	102	136	8.81	0.001
Control	80.32	50	110	16.20		81.94	64	106	12.26	

Table 6 shows that the average Quality of life of the thalassemia children in the intervention group initially was 80.88, with the lowest score being 53, the highest 114, and with a standard deviation of

16.62. Meanwhile, the control group average was 80.32, with the lowest score of 50 and the highest 110, and a standard deviation of 16.21. A  $p$ -value of  $0.873 > \alpha$  (0.05) was reported; hence, the null hypothesis is accepted, which means there was no difference in the Quality of life of patients in the intervention group and control group in the initial measurement before the implementation of the transcultural nursing model in the intervention group. Based on the initial measurement result, both the intervention group and the control group children had a poor quality of life. The mean score of Quality of life in thalassemia children in the intervention group in the final measurement was 118.22, the lowest being 102, the highest 136, and with a standard deviation of 16.62. Meanwhile, the control group's mean score was 81.94, with the lowest being 29 and the highest 106, and a standard deviation of 12.26. A  $p$ -value of  $0.001 < \alpha$  (0.05) was reported; therefore, the null hypothesis is rejected, which means there was a difference in the Quality of life between the pediatric patients in the intervention group and control group in the final measurement. Transcultural nursing model influenced to improve the Quality of life in children with thalassemia.

### Discussion

Nursing theory or nursing model is a theory that underlies how a nurse applies nursing practices Marilyn R, Hiba B [16]. Leininger's model, known as the Sunrise Model, is one of the theories applied in nursing practice. Leininger defines "transcultural nursing" as being focused on the analysis of cultural and subcultural differences by respecting the values of caring, nursing care, health and illness, patients' beliefs, and behavioral patterns [11]. The purpose of transcultural nursing is to develop a humanistic, scientific relationship so as to create culture-specific nursing practices on a specific culture and universal culture of a certain community. Transcultural nursing emphasizes the application of nursing to clients with different cultures, recognizing that culture has an important role and great influence on every client's life [17].

In addition, the perception of patients and families of health and illness depends on their respective cultures. Hence, it is important that the concept of transcultural nursing is applied in nursing practice [18]. The values of patients of the western culture, for instance, are very different from those of the eastern culture. Eastern culture still strongly uphold the customs, habits, myths, and taboos as well as norms that prevail in the community [19]. The cultural values held by individuals, families, and communities are essentially useful to ensure the Quality of life in the people concerned, so they are able to improve their welfare, ensure their physical, mental, and emotional health, and in turn able to interact in the community [20].

Varni, Limbers, Quality of life of children, in general, is influenced by several factors such as: first, the global conditions that include the macro environment in the forms of government policies and principles in the society that provide protection policies for children [14]. The second factor is the external condition that includes the neighborhood (weather, season, pollution, population density), socioeconomic status, health service, and parent education. The third factor is the interpersonal condition. This factor encompasses social relationships between family members, such as parents, siblings, and even other relatives who live in the same house and peers in a child's neighborhood. The fourth factor is the personal condition, covering the physical, mental, and spiritual dimensions of the children themselves, namely genetics, age, sex, race, nutrition, hormone, stress, learning motivation and education, and religious teaching.

Meanwhile, health-related Quality of life describes the condition of healthy physical, social, and emotional functions, which can be measured by a variety of carefully designed instruments that have been measured for their validity. With regard to the present research, measurement or assessment of

Quality of life is important for people with thalassemia in order to improve the management of the disease and improve the Quality of life [21]. The results of measurement of Quality of life with an instrument that has been tested for its reliability and validity can provide useful information to complete clients' data, especially those who experience chronic conditions and require long-term treatment and care so that the intervention given is following the condition of the clients [22].

Chronic conditions in children with thalassemia create great psychosocial problems for patients and even their families. Indeed, the emergence of a disease in physical and psychosocial maturation can interfere with the Quality of life of a person; the person may show some physical, psychological and social symptoms [23]. The long, frequent, and painful treatments at the hospital and the uncertainty of the future have serious implications for the person's health as well as his or her Quality of life [3]. Ismail (2010), with the Pediatric Quality of Life Inventory (PedsQL) found that the negative impacts of physical, emotional, and school functions in beta-thalassemia major patients were worse than those in healthy children as controls. Children with chronic physical disease, especially those with thalassemia, are prone to emotional and behavioral problems. The onset of illness, routine treatment, and the frequency of school absenteeism make the children become emotionally very dependent upon their family, friends in the home environment, and friends in school. Several studies have reported that 80% of children with beta-thalassemia major may have psychosocial problems such as resistance, anxiety, and depression [3].

In this study, the implementation of transcultural nursing care to children with thalassemia modified Koentjaraningrat's concept of culture, Leininger's transcultural nursing, and the concept of thalassemia. The research began with an assessment of the nursing data focused on the cultural elements that are closely associated to the treatment of thalassemia, including the language mastered and used daily, religious elements and beliefs about health and sickness, social element and community system, as well as knowledge about thalassemia. Culture influences the health status of children, as there is a direct correlation between culture and knowledge. The negative culture of a community can lead to a negative impact on the health of the community, although the culture might be considered good by the community. Take for example, a negative culture related to children's health: communities' belief in the negative myths can influence the parenting belief of families so that when the children have some health problems, not a few of the families take their children to a shaman instead of health services.

There are seven elements of universal culture: 1) Language, 2) Knowledge System, 3) Community System or Social Organization, 4) Living Tools and Technology System, 5) Livelihood System, 6) Religious System, and 7) Art (Koentjaraningrat, 2009). These elements correspond to those in the concept of Leininger's transcultural nursing, namely: 1) Culture, 2) Cultural Values, 3) Cultural differences in nursing care, 4) Ethnocentrism, 5) Ethnicity, 6) Religion, 7) Care, 8) Caring, 9) Cultural Care, and 10) Cultural Imposition [11]. In addition, there are standards of practice for culturally competent nursing care, which are as follows: Standard 1: Social Justice, Standard 2: Critical reflection, Standard 3: Knowledge of cultures, Standard 4: Culturally competent practice, Standard 5: Cultural competence in health care systems and organizations, Standard 6: Patient advocacy and empowerment, Standard 7: Multicultural workforce, Standard 8: Education and training in culturally competent care: Standard 9: Cross-cultural communication, Standard 10: Cross-cultural leadership, Standard 11: Policy development, Standard 12: Evidence-based practice and research [18].

Transcultural nursing is an essential aspect of healthcare [24]. This requires nurses to recognize and appreciate cultural differences in healthcare values, beliefs, and customs. Nurses must acquire the



necessary knowledge and skills in cultural competency. So, a culture of nursing refers to the learned and transmitted lifeways, values, symbols, patterns, and normative practices of members of the nursing profession of a particular society [17]. To serve the unique and diverse needs of patients in the United States, it is imperative that nurses understand the importance of cultural differences by valuing, incorporating, and examining their own health-related values and beliefs and those of their health care organizations, for only then can they support the principle of respect for persons and the ideal of transcultural care. Hate and increasing intolerance does not make our goal to provide culturally congruent health care easy in our health care setting [25].

Measurement Model was designed as a modular approach to measuring pediatric health-related Quality of life, developed to integrate the relative merits of generic and disease-specific approaches [14]. The results of this research show that before the treatment with the transcultural nursing model in the intervention group, only half of the children respondents (50%) with thalassemia had a good quality of life. Meanwhile, after the implementation of the transcultural nursing model, most children with thalassemia (78.1%) had a good quality of life. This finding suggests an increase in the Quality of life before and after the treatment of thalassemia with the application of the transcultural nursing model. Compared to the control group that was not treated with transcultural nursing model, the initial measurement indicates that less than half of the thalassemic children (46.9%) had a good quality of life, while in the final measurement, half of the children (50.0%) had a good quality of life. This result suggests that there was almost no change in the Quality of life of the children. These results support Leininger's theory, which explains that cultural care is concerned with the cognitive ability to know about the values, beliefs, and expression patterns used to guide, support, or provide individual, family, or group with the opportunities to sustain health, to be healthy, develop and survive, to live within limitations and achieve death peacefully, especially in patients and families of children with thalassemia.

The results further show that the Quality of life of the thalassemic children before the intervention with transcultural nursing on average scored 80.88, with 53 as the lowest score, 114 the highest, and a Standard Deviation (SD) of 16.62. Meanwhile, after the implementation of the transcultural nursing model, there was an increase in the Quality of life, reaching an average of 118.22, with the lowest score of 102, the highest 136, and a standard deviation of 8.8. The results also indicate that the  $p$ -value was  $0.001 < \alpha (0.05)$ ; hence, there was a difference in the Quality of life in the thalassemic children before and after the implementation of the transcultural nursing model. On the other hand, the Quality of life of thalassemic children in the control group in the initial measurement on average scored 80.32, with the lowest value of 50, the highest 110, and a standard deviation of 16.20. The final measurement demonstrates that there was almost no increase, in which the average score of the Quality of life was 81.94, the lowest score being 64, the highest 106, and with standard deviation of 12.26. Furthermore, a  $p$ -value of  $0.109 > \alpha (0.05)$  was reported, which means there was no difference in the Quality of life in the children with thalassemia in the control group between the initial and final measurements.

These results suggest that the application of nursing with a transcultural approach is a major direction in nursing that focuses on the analysis of different cultures and subcultures in the world that respect caring, nursing services, values, beliefs about health-sickness, and patterns of behaviors that aim to develop a scientific and humanistic body of knowledge in order to provide nursing practices in certain cultures and universal cultures. The transcultural nursing theory emphasizes the important role of nursing in understanding a client's culture [18]. Research on school-age children with thalassemia

shows that school function is the domain factor with the lowest score compared to other domains of Quality of life [23, 26].

The present research results on the comparison of the Quality of life in children with thalassemia show that in the initial measurement, the intervention group averaged 80.88, with the lowest score of 53, the highest 114, and a standard deviation of 16.62. Meanwhile, the average score in the control group was 80.32, with the lowest score of 50, the highest 113, and a standard deviation of 16.20. Furthermore, a  $p$ -value of  $0.873 > \alpha (0.05)$  was reported; hence, there was no difference in the Quality of life in patients between the intervention group and control group in the initial measurement prior to the implementation of the transcultural nursing model in the intervention group. This finding indicates that in the initial measurement children in both the intervention group and the control group had a poor quality of life equally. On the other hand, the score of Quality of life in the intervention group children with thalassemia in the final measurement on average was 118.22, with the lowest score being 102, the highest 136, and a standard deviation of 16.62. Meanwhile, the average score in the control group was 81.94, with the lowest being 64, the highest 106, and a standard deviation of 12.26. In addition, a  $p$ -value of  $0.001 < \alpha (0.05)$  was obtained; thus, there was a difference in the Quality of life between patients in the intervention group and control group in the final measurement. Herein, it can be concluded that the application of the transcultural nursing model has an influence on the improvement of Quality of life in children with thalassemia.

Based on the results of the research, it can be seen that nurses' correct understanding of a client's culture, whether as an individual, family, group, or community, can prevent the occurrence of culture shock and cultural imposition, where nurses learn or adapt effectively to the client's cultural group. There are times when nurses can apply the cultural values, beliefs, and habits/behaviors that the client has as an individual, family, or community group. This shows that the nurses believe that a cultural approach has a greater potential to result in the successful treatment of the individuals and families, especially in patients with thalassemia [18]. Nurses need to understand that school-age children with thalassemia often skip school because they have to undergo a routine transfusion, in which the lower the hemoglobin level of the child longer the transfusion time will be [27, 26]. Even some thalassemic children who often skip school will eventually drop out of school [28].

### Recommendation

Recommendations are made: (1) For associate nurses who care for thalassemia patients, they should be informed about the meaning, nature, and cultural significance of each application of the transcultural nursing model and understand the culture of every patient and his/her family; (2) For nursing education, it is necessary to introduce a transcultural nursing model to students in the application of nursing care to patients, especially children with thalassemia.

### Conclusion

The conclusions that can be drawn from the research are: (1) There was a difference in the Quality of life of the children in the intervention group before and after treatment with the transcultural nursing model; (2) There was no difference in the quality of life of the children in the control group between the initial and final measurements; (3) There was a difference in the Quality of life between the children in the intervention group treated with transcultural nursing model and those in the control group who did not receive treatment with transcultural model; hence, the implementation of the transcultural nursing model has an influence on the Quality of life in the children with thalassemia at HasanSadikin Hospital, Bandung.

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**Competing interests**

The authors declare that they have no competing interests.

**Aut**<sup>27</sup>**'s contributions**

HC participated in designing and data collection, analysis, and interpretation of data, writing, and submitting the article for publication. AH participated in data collection, supervised and reviewed the technical and methodological aspects of this study.

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