Original Article

Experiences of the Parents of the Children with Cancer: A Qualitative Study

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Abstract

Aim: The aim of this study was to investigate the experiences of the parents of the children with cancer.
Method: In this study, one of the qualitative research methods was used. The interviews were conducted with the parents (6 mothers, 6 fathers) of the children who aged 7-11 years, received chemotherapywere and diagnosed with cancer at least six months ago. In order to analyze the data, content analysis method was used as a qualitative data analysis method.
Results: According to the families, the disease is an act of God; they praise because worse conditions could be developed; this disease may be a familial disease; the disease may develop because of excess breastfeeding, jealousy in the family or evil eye.
Conclusion: In conclusion, the parents of the children with cancer faced many negative situations during the diagnosis and treatment process of the disease.

Keywords: cancer, child, chemotherapy, parent, experiences

Introduction

Childhood acute lymphoblastic leukemia (ALL or acute lymphocytic leukemia) is the cancer of the blood and bone marrow. This type of cancer usually deteriorate fastly if not treated (National Cancer Instute, 2018). Leukemia cells can also be spread into the bloodstream and metastasize to the lymph nodes, spleen, liver and other organs. (Children's Oncology Group, 2011). There are different types of treatment for childhood acute lymphoblastic leukemia (ALL). Four types of standard treatment such as chemotherapy, radiation therapy, chemotherapy with stem cell transplantation and targeted therapy are used (National Cancer Instute, 2018). In September 2018, it aimed to achieve a survival rate of at least 60% for children with cancer until 2030, thus one million lives can be saved according to the World Health Organization. Cancer is one of the leading causes of child death; 300,000 new cases between the ages of 0-19 are diagnosed each year. Children with cancer in low- and middle- income countries are more likely to die from the disease compared to children with cancer in high-income countries. The reason is that the disease can not be diagnosed, the treatment is usually given up due to high costs, health care professionals who are responsible with care do not receive specialization training (WHO, 2018).

According to the American Cancer Society (2018) and the National Cancer Institute (2017), 29% of childhood (0-19 years) cancers comprise leukemias (https://curesearch.org/Number-of-Diagnoses). The incidence of ALL in the United States is estimated as 1.6 per 100,000 individuals (National Cancer Institute; SEER cancer statistics review 1975-2013). In the United States, approximately 3,250 children are diagnosed with leukemia every year, 2400 of them are ALL. 1200-1500 new cases of leukemia in children under the age of 16 are reported every year in Turkey (Children's Leukemia Foundation, 2017). The incidence of acute lymphoblastic leukemia in the children between the ages of 0-14 years in Turkey has been reported as 41.4/1000000 (Kutluk, 2007).

It shows that the symptoms that develop after chemotherapy adversely affect the patients' life quality, they have difficulties in maintaining their daily lives (Arslan, Yiğit, & Temel, 2014). Cancer is a disease that affects patients, their families and their social environment. There are many studies on the mental state of children with cancer and their parents (Lahteenmaki, Sjöblom, Korhonen, & Salmi, 2004). Psychiatric problems such as depression, anxiety, stress (Muscara, McCarthy, Woolf, Hearps, Burke, & Anderson, 2015), sleep disturbance, physical complaints and depression are very common especially in parents of cancer children (Lahteenmaki, Sjoblom, Korhonen, Salmi, 2004;). From the diagnosis of cancer in children, parents of children with cancer are deeply affected. Although depression and anxiety decrease after years, these mental problems continue. Therefore, good psychiatric support should be given to their parents. In addition, it is also very important that parents support each other. From the diagnosis of cancer, both children and their families are affected negatively. In parents, especially the fear of losing a child leads to severe anxiety (Bahadir and Kurucu, 2015). The aim of this study was to investigate the experiences of the parents of the children with cancer.

Materials and Methods

In this study, one of the qualitative research methods, phenomenology method was used. Phenomenology method was used to investigate the facts that we are always aware of but do not know in depth (Yildirim, & Simsek, 2013). In this study, the phenomenon was the emotional state of the parents and the children who were diagnosed with ALL and received treatment from the perspective of the parents according to how they are affected during the diagnosis and treatment process of parents.

Sample: In order to achieve the objective of the study, the interviews were conducted with the parents (6 mothers, 6 fathers) of the children who were between the ages of 7-11 and who were diagnosed with cancer at least 6 months ago who were receiving chemotherapy treatment at Dicle University's Pediatrics Hospital Hematology Clinic by using criterion sampling method.

Data Collection Tools: In the data collection, the intodutory information form was used for the parents of the children with ALL while the structured interview form was used to determine the situations experienced by the parents before the diagnosis and for the first time they had heard the diagnosis. The structured interview form consisted of 11 questions according to expert opinions. Interview with each parent took 25 minutes. The parents were asked the following questions during the intervies.

How did you notice your child with ALL?
What did you feel when your child was diagnosed with ALL?
Who did you firstly share with when your child was diagnosed with cancer? Who did you receive support at most?
Did you receive sufficient support from health professionals?
How was your partner and children affected by this process?
Did your sexual life change?
What was the reaction of the people around you?
Is there a specific cause of this disease?
What did develop in your child and you during the treatment process?
What were the most frightening complications seen in your child during the treatment process?

Data Evaluation: In the data analysis, content analysis method was used as a qualitative data analysis method. Content analysis is basically to bring together similar data within the framework of specific concepts and themes and to interpret them by organizing them in a way that the reader can understand. In the content analysis, there are four stages of processing of qualitative research data obtained from the documents as data coding, finding themes, editing codes and themes, identifying and interpreting the findings (Yildirim and Simsek, 2008).

Ethical Approval: The study was approved by the Ethical Committee for Non-invasive Clinical Studies of the Dicle University Medical Faculty (Date: 25.01.2018 / Issue: 56). Oral and written permissions were obtained from children's hospital. Verbal and written consents were obtained from the parents who met the inclusion criteria and who accepted to participate in the study. The written consents were obtained from the patients' relatives by using the Informed Consent Form containing the information about the purpose, time and implementation of the study, data collection, voluntary participation, the right for leaving from the study at any time and the confidentiality of personal identifying information.

Acknowledgment: Thank you so much to the mothers for the information that they agreed to participate in the our research.

Limitations of the Study: The limitations of the study are lack of generalization due to single center study and the inability to interview with the parents who did not agree to participate in the study.

Results

When the data obtained from the interviews are analyzed by the content analysis method:

1. Developments in the diagnosis process

2. Conditions which developed during the treatment process

Two themes emerged. The categories and codes obtained from these themes are presented in the tables below, respectively, and the opinions of each parent are represented by symbols such as E1, E2, E3, En; the opinion of the researcher is shown with letter A.

Conditions which developed during the treatment process

The categories obtained under the theme of the development process in the process of diagnosis which is one of the themes obtained from the interviews with the parents are grouped under 3 headings:

- The recognition process of the disease
- Thinking process about the cause of the disease
- Support process

These categories are examined respectively below.

The Recognition Process of the Disease

Detailed information about the process of recognizing the disease is shown in Table 1 together with their frequencies.

When Table 2 is viewed, It can be said that 3 codes as physical changes, psychological changes and the family's mood were identified. It was determined that physical changes were observed in different ratios by parents as mentioned in Table 1 above. 41% of the sample (n=5) stated that they realized the disease as a result of the negative changes in their children blood values and the bruises in various parts of their bodies. 33% (n=4) of the parents stated that they realized the disease as a result of inappetency of their children. 25% 'of the parents stated that they suspected and realized the disease as a result of fatigue, knee pain, fever of their children. The parents expressed their opinions as follows:

E3: *My child had a fever for 3 days a fever and his forehead was too hot when I put my hand on her/his forehead. She/he had a runny nose like flu, his siblings had the flu, therefore we thought that this condition was normal.*

E5: *Her/his skin color was yellow, he/she had abdominal pain, her/his bleeding did not stop, bruises and pain in her/his legs, he/she was weak and inappetent.*

In Table 2, it can be said that the psychological status of the children changed during the diagnosis phase of the disease. One of the parents said that the child was very nervous during this period and another said that they noticed that the child was crying during this period. They declared their thoughts as follows:

E10: *There were bruises on her/his head, back, abdomen. She/he had abdominal pain, fever, and cried a lot.*

E4: *There were bruises on her/his abdomen, arms and back; he/she was inappetent, weak and nervous and vomited once in the school; she/he was coughing; her/his throat swelled.*

Another code which was obtained during the process of recognizing the disease was the changes in the emotional status of the family members during the process of recognizing the disease. According to Table 2, the familes stated that they were very sad (n=3), shocked (n=2) because of the negative conditions developed in their children diagnosed with ALL; some of them stated that they began to adapt this condition in time (n=1).They expressed their feelings about this situation as follows:

E5: *I felt terrible, I was confused at what to do, I felt I was going to lose her/him then I was thankful because he was alive. I was desperate. I was devastated. There were bad examples of this disease all around me, and the patients with this disease did not live very long. My mother's brother's grandson had died while he had been* *waiting bone marrow transplants, so I had no hope. I didn't believe my child could get better. Some people around me said that he was going to be okay, but I didn't believe them. It seemed that I was in a nightmare, I had a bad dream.*

E11: *I did not slept 3 nights and I was crying all the time. He/she was my first child, you know, firstlings had special place in their parents' heart.*

It can be said that the parents experienced shock, they did not accept the disease, they were sleepless according to their comments about the process of recognizing the disease.

Familial Cause of the Disease

One of the categories that emerged during the diagnosis process was the familial cause of the disease. Detailed information about this category is shown in Table 3.

In Table 3, 50% of the parents (n=6) stated that the disease was the act of God. Two parents stated that the disease was the act of God to encorurage them to praise. They expressed their thoughts as follows:

E8: *It is destiny and the act of God.*

E1: *God gave us this disease to praise*

In addition, 0.1% (n=1) of the parents stated that they did not know the cause of the disease, it was probably because of excess breastfeeding, jealousy. One parent stated that cancer was caused by more than one reason while another parent stated that the disease was caused by the genetic structure. The parents' opinions as follows:

E2: *I accepted this disease as an exam from God to test us. I breast-fed my child excessively and sometimes I thought that the disease as a result of it.*

E12: *My mother-in-law is a breast cancer patient, cancer is maybe familial in our family.*

E5: *7-8 years ago, me and my brother married at the same time, but my brother did not have a son, but i have a son. My aunt-in-law was jealous of us. My child was constantly sick. My child infected so many times since his babygood and he was also hospitalized for several times. Others were jealous of my child because my child is male.*

E7: *I've never heard of this disease before. I just thought that why it happens in children.*

E10: *There is no special reason. A very difficult disease which can happen to anyone. i wouldn't wish that on others.*

As seen in the comments above, it is seen that parents generally thought that the disease was the act of God, but some parents also had different ideas obout the cause of the disease such as jealousy, excess breastfeeding.

Supporters

The most recent category in the diagnosis process as "supporters". The details about the category are given in Table 4.

When the findings obtained from the diagnosis process were analyzed, almost all of the participants stated that their families and health institutions supported them.

E2 stated that he/she did not get support from his/her family during the treatment period, expressed his feelings as follows:

E2: *There was no one to get support, I was completely alone ... i praised.*

E3, who said that he/she got support from his/her family, expressed his/her feelings as follows:

E3: *I called my brother. Especially, my own family gave me so much support. My dad gave me so much morale, my mother did the same. But I got the most support from my brother.*

E2, who said that health workers support themselves in the diagnosis process, stated their feelings as follows:

E2: *We got support from nurses and doctors working here*

Some parents who are satisfied with the support of healthcare organizations also stated that inexperienced doctors had a negative impact on the treatment process.

E6: *Some of them were good and some of them were very novice. Therefore, they hurt my child. I didn't want that novice doctors harvested the bone marrow of my children. Especially, when they placed the port, it hurt very much and cause lots of inflammation. This situation was because of the novice doctors.*

***E5:** The nurses here are very nice and they treated us very well, but I don't like the manner of speaking of some doctors.*

In the light of the above comments, it was determined that the parents were supported by their families and health institutions during the diagnosis process but one of them did not receive support from his/her family.

Developed Conditions during the Treatment Process

As a result of the interviews, 3 categories were obtained under the findings obtained during the treatment process, they are shown in the table, respectively:

- Developed conditions during the treatment process
- The response of the Social Environment and the conditions developed in the environment

These categories were analyzed, respectively.

Developed Conditions in the Family during the Treatment

As a result of the analysis of the data obtained from the interviews, the category of "the conditions developed in the family during the treatment process" was determined. This category is clearly shown in Table 5.

According to table 5, it can be said that other children and parents in the family are negatively affected during the treatment process.

According to the category related to other children affected by sick children in their families, it is observed that the children were affected by the condition of their siblings; the parents experienced weariness and failure and this rate was 50% (n=6). In addition, Inability to take care of other children due to the required mother's care for the child undergoing ALL is one of the main problems in the family. Table 4 shows that this rate was 75% (n=9). The parents expressed their feelings about these situations as follows:

***E4:** My children are mentally depressed, my daughter cries all the time. At the first months, I mostly nursed my child with ALL; i could not see my other children; grandmothers and aunts looked after them. They constantly cried. My eldest daughter's school success fell down.*

***E6:** My wife was pregnant at the time, and she stayed with my child in the hospital. She stayed in the hospital after birth; she looked after both the baby and our child with ALL. I stayed at the hospital masjid with my children. Therefore, my other children could not go to school all had to leave school. We're ruined.*

As can be understood from the parental comments, it can be said that the parents and other members of the family were negatively affected by this condition.

According to the code of the conditions observed in the mother or father, it was determined that one of the most remarkable findings were related to sleep. The sleep pattern was disturbed and the parents' sleeping time was changed in respect to the sleeping and drug time of the child with ALL. The opinions of E2 and E3 related to this condition are as follows:

***E2:** I sleep at 1 o'clock every night after giving my child's medication. Even if there is no drug, i can not sleep before 1 o'clock . I wake up at 6:30-7:00 in the morning. I sleep 6 hours on average.*

***E3:** I sleep at 1:00 every night to give the drugs to my child, I wake up at 7:00 in the morning. I sleep 6 hours a day on average.*

According to the frequency of the statements, 41% (n = 5) of them had adversely affected sexual lives, E1 and E7 made the following comments related to this condition:

***E7:** Yes, our sexual life has been adversely affected.*

E9 made this comment on his sexual life during the treatment process:

***E9:** We were bad at first. Then there was no problem.*

It was found that the parents (n=3) adapted to the treatment process during the process. The E5 made the comment below for this condition:

***E5:** First 3 months, my child cried because i did not go to her/his, but me and my child adapted to this condition in time. I bought everything what my child wanted because i did not want to make my child sad. I could not kiss and hug my child for 2 years, it's a very difficult thing for me.*

In the course of the treatment, it was found that the parents felt like they were ruined (n = 3). E1 stated her/his feelings as follows:

E1: *The roof fell in, I was very sad then i praised. At first, we did not believe the treatment, we refused it. We went to Damascus/Syria; they said the same thing according to the blood tests and bone marrow findings, then we came here.*

During the course of the treatment, it was determined that the mother got pregnant for the combatible bone marrow, could not sleep, could not believe in the diagnosis, tried to be positive and had difficulties. The comments of E9 and E8 regarding these situations are given below:

E9: *I always looked optimistically. So my child is thankfully so good, but we had a lot of financial difficulties.*

E8: *I can't sleep, I check my child as if something happen to her. I wake up from time to time*

E3: *I had hard times. I got pregnant for the bone marrow transplant, and I stayed in the hospital with my child. I cared for my child in this hospital. I gave birth, my sister came; she sometimes came and helped*

Complications Developed in the Children During the Treatment

In the course of the treatment, the complications in the child were collected under two codes:

- Physical Complications
- Mental Complications

The physical complications observed by parents during the treatment period were according to their frequencies as follows: weaknes 41% (n=5), mouth sores 33% (n=4), not eating 25% (n=3), fatigue, hit and fall 16% (n=2) and adenoids, stomachache, bone weakening, weight loss and nausea 1% (n=1). The comments of E2 on this condition are as follows:

A: *What are the most frightening complications seen in your child during the treatment?*

E2: *Nausea, vomiting and mouth sores*

E10, E3 and E5 made the following comments about the remarkable complications related to this condition:

E10: *She did not eat and had many mouth sores.*

E3: *My child was very tired in the 4th course of the treatment, he had seizure, he was constantly asleep and weak. I was so scared at that time.*

E5: *When he walked, he hit around him, his weakness and tiredness scared me.*

If the psychological complications developed in the child with ALL were evaluated according to their frequency, 25% (n=3) of them adapted to the condition in time, 16% (n=2) of them cried, 1% (n=1) were mentally depressed and did not talked, respectively. The opinions of E4 and E8 regarding the mental complications in the children undergoing ALL treatment are as follows:

E4: *My child constantly cried, felt pain, was tired probably due to the effects of the drugs. Her bones ached, could not walk but adapted to it in time.*

E8: *He did not talked, was weak, sometimes good and sometimes bad. This condition frightened me. My child was mentally depressed, but I tried to reassure him. I tried to buy everything he wanted. I tried to not upset him.*

According to the interviews, physical and mental complications in the children undergoing ALL treatment were recognized by their parents; this condition negatively affected both the parents and their family members and the children undergoing ALL treatment.

Response of the Environment and the Conditions Developed in the Environment During the Treatment

One of the situations that occurred during the treatment period was the category of environmental response. The response of the environment was analyzed by two codes, positive and negative. The information about this category is given in Table 7 in detail.

In Table 7, it was found that the environment showed a positive attitude towards the children who receiving ALL treatment as help and support; this ratio was found to be 3 (n=4).

E1: *People acted sensitively.*

E4: *Everyone such as my family, my spouse's family, our relatives and neighbors were constantly offered help and acted sensitively.*

It was also found that the rate of intervening to the children with ALL like to intervene to patients with infectious diseases, acting insensitively to them and not supporting them was 58% (n=7). The opinions of E11, E9 and E5 are given below:

E11: *They didn't support me. My siblings did not support me, why did the neighbours support me?*

E9: *No one gave us a leg up. According to an old saw, he who falls has no friends; i understood that this is also a fact for the disease. Everyone was afraid of cancer. Everyone kept away from my child as if he had an infectious disease. This made us very uncomfortable.*

E5: *Noone acted sensitively except my father, my brother-in-law and my elder brothers. They accepted cancer as a normal disease. They didn't pay attention about infection. They thought that we exagerated the disease. The relatives were not sensitive at all.*

As a result of the analysis, the parents experirenced two processes as diagnosis and treatment; recognizing the disease and thinking about the cause of the disease during these processes.

Table-1: Sociodemographic Characteristic of Parents

Characteristics	**n**	**%**
Woman (Mother)	6	53.3
Man (Father)	6	46.7
Education Level of Mother		
Illiterate	3	25.0
Primary School	6	50.0
Middle School	1	8.3
High School	2	16.7
Employment Status		
Employed	6	50.0
Unemployed	6	50.0
Economical Status		
Good	1	8.3
Middle	6	50.0
Poor	5	41.7
Disease of the Children ALL	12	100.0
	Mean ± SS	**Min-Max**

Age of the Parent	34.90±4.52	27-45
Age of the Child	8.00±1.90	4-11
Years of the Disease	2.90 ±2.38	0.6ay -9 yıl

Table 2 ***Noticing the Disease***

Category	**Code**	**Description**	**Frequency (f)**
Recognition Process of the Disease	Physical Changes in the Child	Knee pain	3
		Lumbar pain	1
		Inappetency	4
		Vomiting	2
		Negative Changes in Blood Values	5
		Fever	3
		Nasal Discharge	2
		Bruises	5
		Asthenia	3
		Adenoids	2
		Cough	2
		Yellowish Skin Color	2
		Stomachache	2
		Continuous Bleeding	1
	Mental Changes in the Child	Nervousness	1
		Crying	1
	Emotional Status of the Family	Being Thankful	2
		Adaptation	1
		Being Shocked	2
		Being so sad	3

Table 3 Familial Cause of the Disease

Category	**Code**	**Description**	**f**
Familial Cause of the Disease	Divine	To attribute the cause of the disease to the religion	6
	For praising	To be grateful that there is no worse	2
	Genetical	To think that there is a family disease	1
	Excess breastfeeding	To think that the child has this disease because of excess breastfeeding	1

	Not knowing the cause	Not know the cause of the disease	1
	No particular cause	To think that there is no specific cause of the disease	1
	Jealousy	To think that the disease is caused by situations such as jealousy and evil eye within the family.	1

Table 4 Supporters

Category	**Code**	**Description**	**f**
Supporters	Family	Support from the family members such as father, siblings, spouse and uncle	11
	Healthcare Organization	Support the health staff	12

Developed conditions during the treatment process

Table 5 Developed Conditions in the Family during the Treatment

Category	**Code**	**Description**	**f**
In family	Other Children of the Family	Being affected by ill siblings, wearing down, doing badly at school	6
		Inability to take care of other children due to the required mother's care for the sick child	9
	Developed Conditions in the Mother or Father	Sleep problems, having a sleep pattern according to the time for taking medication	10
		Getting pregnant for bone marrow compatibility	1
		Adaptation to the process	3
		Experiencing financial difficulties (by the family)	2
		Negative effect on sex life	5
		No effect on sex life	2
		The roof falls in	3
		Disbelieve	1

		Trying to be positive	1
		Not sleeping	1
		Uneasiness	1

Table 6. Complications Developed in the Child with ALL during the Treatment

Category	**Code**	**Description**	**f**
Complications Developed in the Child	Physical Complications	Weakness	5
		Mouth sore	4
		Not eating	3
		Fatigue	2
		Fall, Hit	2
		Adenoids	1
		Stomachache	1
		Bone Weakening	1
		Weight Loss	1
		Nausea	1
	Mental Complications	Crying	2
		Being mentally depressed	1
		Not talkinh	1
		Adapting to the Condition in time	3

Table 7. Response of the Environment and the Conditions Developed in the Environment During the Treatment

Category	**Code**	**Description**	**f**
Environmental response and environmental conditions	Positive attitude	Helping, Supporting	4
	Negative attitude	Staying away, Intervening to the condition like an infectious disease	7

Discussion

Although the survival rate in childhood cancers have relatively increased compared to previous years, they are potentially life-threatening. The course of diagnosis and treatment brings great challenges for bot the children and their families (Wallace, 2004).

In this section, the categories and themes formed by the data obtained from this study which was conducted to determine the experiences of the parents of the children diagnosed with ALL were discussed with the studies in this field but the number of studies in this field was limited, therefore the qualitative study examples which conducted with the individuals diagnosed with similar diseases and their families. The parents had the feelings such as grief, thanksgiving, being shocked and adaptation when they first heard of the disease. In a study by Karakavak and Cirak (2006), the mothers of the children with chronic diseases stated that they felt shocked, confused, frustrated, rejection, despair, fear when they first learned their children's chronic disease; they were depressive and sometimes angry against the God because of the course of the disease (Karakavak,& Cirak 2006).

These data are in consistent with the results of the study. One of the categories that emerged during the diagnosis process was familial cause of the disease. The parents linked the cause of the disease to the religion. They stated that the disease was divine (a test from the god); they were thankful because this condition was not worse; it was a familial disease; it was caused by excess breastfeeding; the disease was caused by conditions such as jealousy and evil eye within the family. In Faulter's study (1998), the families nursing for the cancer patients and cancer patients could perceive cancer as the test of God to examine the patients and their families. The anger and frustration of the person with cancer is the emotional reactions against God (Faulter, 1998). In a study by Karakavak and Cirak (2006), it was revealed that the mothers of children with chronic diseases isolated themselves and could not accept this condition for a while (Karakavak and Cirak 2006).

Karavak and Cirak (2006) stated that mothers shared their needs and feelings with their spouses and children, but their interest in other children decreased and they did not have enough time for them because of increased hospitalizations of sick children. They stated that they received support from their relatives for the care of other children in cases of surgery and treatment (Karavak and Cirak, 2006).

In the study of Eiser et al. (2005), it was stated that the families had to isolate themselves due to the fear of infection in their children and the fatigue of the children after the diagnosis (Eiser et al., 2005). In this study, the parents stated that siblings, spouses, uncles and healthcare staff also supported them during the disease. In this study, the mothers were not able to devote time and care to other children due to taking care of the sick child. The results of this study are similar to the findings in the literature. The presence of a patient struggling with cancer in the family changes the family's roles, daily life routines and interactions in the family as well as causing adaptation problems to new situations (Terakye, 2011).

The social, economic and emotional consequences caused by chronic diseases are important for sick children and their families and they may arise in a very different way. In this very difficult process, the role and responsibilities of nursing become important (Kayhan, 1995).

As a result, parents having children with cancer face many problems during the treatment of the disease.

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