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Araştırma Makalesi–Research Paper

EFFECTIVENESS OF INDIVIDUALIZED EMPOWERMENT EDUCATION ON CHILDREN WITH BETA-THALASSEMIA MAJOR: A MIXED-METHOD STUDY

BETA TALASEMİ MAJÖR TANILI ÇOCUKLARDA BİREYSELLEŞTİRİLMİŞ GÜÇLENDİRME EĞİTİMİNİN ETKİNLİĞİ: KARMA YÖNTEMLİ BİR ÇALIŞMA

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Özet

Bu çalışmada, Beta Talasemi Majörlü (BTM) 12-18 yaş çocukların hastalık süreci ile ilgili gereksinimlerinin belirlenmesi ve bu gereksinimlere yönelik verilen bireyselleştirilmiş güçlendirme eğitiminin etkinliğinin incelenmesi amaçlanmıştır. Bu araştırma karma tipte bir çalışmadır. İlk aşamada BTM'li çocukların hastalık süreci ile ilgili sorunlarının ve ihtiyaçlarının belirlenmesi amaçlanmış olup, fenomenolojik yöntem kullanılmıştır. İkinci aşamada, tek grupta ön/son test kontrollü yarı deneysel yöntem kullanılmıştır. Verilerin toplanmasında, "Tanıtıcı Bilgi Formu", "Yarı Yapılandırılmış Görüşme Formu" ve "Beta Talasemi Majörlü Çocukların Gereksinimlerini Belirleme Soru Formu" kullanılmıştır. İlk aşamada: tedavi süreci, aile süreci ve sosyal yaşam olmak üzere üç tema oluşturulmuştur. Çocuklar eritrosit transfüzyonu öncesi yorgunluk, baş ağrısı, halsizlik gibi sağlık sorunları yaşadıklarını belirtmişlerdir. Ayrıca çocuklar hastalıkla ilgili damgalanma nedeniyle kendilerini mutsuz, üzgün ve öfkeli hissettiklerini ifade etmiştir. Güçlendirme eğitiminin etkinliğinin değerlendirildiği ikinci aşamada ise güçlendirme eğitimi ön test, birinci son test ve ikinci son test toplam puan ortalamaları arasında istatistiksel olarak anlamlı bir fark bulunmuştur (X_2 =26.00, p<.001). Yapılan çalışmanın sonucunda, bireyselleştirilmiş güçlendirme eğitiminin çocukların hastalık bilgisi, tedavi süreci, anne/baba ilişkisi ve sosyal hayata yönelik gereksinimleri üzerine olumlu etkisi olduğu belirlenmiştir.

Anahtar Kelimeler: Beta Talasemi Major, Güçlendirme, Eğitim, Mix-Metod

Abstract

This study aimed to identify the problems related to the disease process of 12-18 years old children with Beta-Thalassemia Major (BTM) and to examine the effectiveness of individualized empowerment education regarding these needs. This research is a mixed-type study. In the first stage, it is aimed to determine the problems and needs of children with BTM concerning the disease process; the phenomenological method was used. In the second stage, the pre/post-test controlled quasi-experimental method was used in a single group. "Descriptive Information Form", "Semi-Structured Interview Form" and "Questionnaire for Determining the Needs of Children with Beta Thalassemia Major" were used to collect data. The first stage, three themes were formed: the treatment process, the family process, and social life. Children stated that they had health problems such as fatigue, headache, and weakness before erythrocyte transfusion. Also, the children felt unhappy, sad, and angry because of disease-related stigma. In the second stage, a statistically significant difference was found between the total mean scores of the empowerment education pre-test, first post-test and second post-test (X_2 =26.00, p<.001). As a result of the study, it was determined that individualized empowerment education had a positive effect on children's knowledge of the disease, treatment process, mother/father relationship and social life needs.

Keywords: Beta Thalassemia Major, Empowerment, Education, Children, Mixed-Method

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1. INTRODUCTION

Beta Thalassemia Major (BTM) is hereditary hypochromic microcytic anemia caused by an abnormality in the structure of the beta hemoglobin chain. This chronic disease is a disease classified according to a genetic defect (Fergus, 2002, pp.11-15). Thalassemia resulted in 25,000 deaths in the world from 1990 to 2013. The birth rate with thalassemia is approximately 365 thousand in the worldwide (Origa, 2017, pp.609-619). According to the records of Thalassemia centers in Turkey, there are a total of 2046 patients in Turkey, 1658 of which have BTM (Aydınok et al., 2018, pp.12-18). While BTM was seen as a fatal disease until recently, today, if adequate health care is provided, the life expectancy of individuals has been extended until adulthood period (Gharaibeh et al., 2018, pp.182-187). The basis of adequate health care is regular erythrocyte suspension transfusion, iron chelation therapy and qualified care that supports this essential therapy. Recent medical advances have strengthened the treatment of thalassemia and supported the care process. This contributed to the quality of life by reducing complications (Shafie et al., 2020, pp.1-11). When the treatment is not applied effectively in thalassemia, anoxia, and splenomegaly, infections increase susceptibility and bone deformities progress rapidly (Fergus, 2002, pp.11-15). In addition to physical symptoms, psychosocial problems also accompany this picture (Chong et al., 2019, pp.15-20). Children with BTM have to cope with leaving their family for long-term treatment hours, limiting physical activities that require effort, bone deformity and the deterioration of the body image it creates. Secondary diseases that develop during the treatment process of the disease cause death anxiety and restrictions in school/play activities. When all these come together, the children's anxiety and depressive mood increase (Mansoor et al., 2018, pp.211-214; Roghani et al., 2018, pp.64-67; Kumar et al., 2019, pp.762-769). In addition, thalassemia can also negative affect individuals, families, and society as well (Zakiyah et al., 2018, pp.238-245). So children need individualized care (Moghadam et al., 2016, pp.357-360). Determining the needs is the starting point of any education and maintenance program (Tarakmeh et al., 2018, pp.59-70). For the management of these negative symptoms and ensuring that the disease process progresses positively, nurses, actively play a role in empowering the child at every stage of care.

This study, it was aimed to identify the problems related to the disease process of 12-18 years old children with BTM and to examine the effectiveness of individualized empowerment education regarding these needs.

2. MATERIALS AND METHODS

2.1. Study Design

This research is a mixed-type study planned in two stages. The first phase is to determine the problems and needs of children with BTM regarding the disease process: the phenomenological method is used.

In the second phase, individualized empowerment education was provided for the necessary issues related to the disease process defined by a qualitative method. In examining its effectiveness, a pretest-posttest controlled quasi-experimental method was used in a single group.

2.2. Study population

This research was conducted at the Thalassemia Unit of a children's hospital in Turkey. The unit is the region's largest and most comprehensive center for BTM treatment. The research population consisted of 30 children with BTM between the ages of 12-18. The homogenous sampling method, which is one of the purposive sampling techniques, was used in the selection of the subjects. Considering the data saturation, 16 children with BTM were interviewed. However, during the preparation of the education sessions, one case was excluded from the study because of bone marrow transplantation, and the study's sampling was completed with 15 children with BTM. Inclusion criteria in the study: (1) being between 12-18 years of age; (2) having not had a bone marrow or stem cell transplant; (3) having no mental health problems; (4) speaking Turkish and participating voluntarily.

2.3. Data collection

In the first phase of the study, An Introductory Information Form, a Semi-Structured Interview Form and a voice recorder were used.

2.3.1 Introductory information form

It consists of 22 questions about the socio-demographic characteristics of the children (age, gender, education level, height, weight etc.).

2.3.2. Semi-structured interview form

The interview form was prepared in line with the literature (Molazem et al., 2016,pp.1-9; Grewal et al., 2017, pp.33-37; Shahraki-vahed et al., 2017, pp.243-251). To ensure the suitability of the questions, 10 expert opinions were received. The pilot study was conducted on three children (these people were not included in the sampling) because of the suitability and comprehensibility of the questions.

2.3.3. Voice recorder:

Sony ICWDPX240.Ce7 brand voice recorder was used for recording the interviews. The voice recorder has a capacity of 32 hours of recording (MP3 8 kbps).

In the second phase of the study, A Question Form for Determining the Needs of Children with BTM, education booklets and education videos were used. Education was given as sessions. Each interactive session was approximately 60 minutes, and its total duration was 360 minutes.

2.3.4. Question form for determining the needs of children with BTM:

A pre-post test question form was used to evaluate the effectiveness of the education.

The data collected with a semi-structured questionnaire for individual interviews were processed, and themes and codes were created. From these themes and codes, the subheadings of the form for determining the needs were created. The questionnaire for determining the needs of children with BTM includes 53 questions, classified under five subheadings (disease knowledge, medical process, family experiences, social life and health service). These answers to the questions were stated as I agree/I disagree. Seven expert opinions were obtained. Reliability analysis was conducted with Kuder Richardson 20 (KR-20) to evaluate whether the items that make up the questionnaire form a whole. For the questionnaires with more than 50 items, the KR-20 reliability coefficient should be above 0.80 (Erdoğan, Nahcivan, & Esin, 2014). Reliability analysis was conducted with Kuder Richardson 20 (KR-20). The KR-20 reliability coefficient was 0.86.

2.3.5. Training booklets:

6 booklets, "Erythrocyte Transfusion Education Booklet for Children with Thalassemia", "Nutrition Education Booklet for Children with Thalassemia", "School Life in Thalassemia Education Booklet", "Psychosocial Process Education Booklet for Children with Thalassemia", "Bone Marrow and Stem Cell Transplantation Education Booklet", "Rights of Children with Thalassemia Booklet" were prepared by the researchers (Molazem et al., 2016, pp.1-9; Grewal et al., 2017, pp.33-37; Shahraki-vahed et al., 2017, pp.243-251; Shamsi et al., 2017, pp.1-7). Seven expert opinions were obtained. Also "All About Thalassemia Education Booklet" were used.

2.3.6. Training videos:

Four education videos were used: "Genetic Transition in Thalassemia", "Treatment Process in BTM", "BTM and Spleen" and "Microbial Susceptibility in BTM". The videos were prepared by the pediatric hematology association. They are available on the official site and YouTube channel of the Association and are open to view.

2.4. Ethical Statement

Prior to the study, written permissions were obtained from İzmir Katip Çelebi University Non-Interventional Scientific Ethics Committee (date: 4/19/2017, Decision number: 89) and the institution where the research was conducted (Number: 23592379-604.02).

Before the interview, the necessary information was given to the children and their parents about the purpose of the study, the time to be spent for the interview and education, and their written consents were obtained. The names of the participants were identified with codes (C1, C2,C3…).

2.5. Data Analysis

In the study's first phase, socio-demographic data were analyzed by number and percentage distribution. Thematic analysis was used for qualitative data. Colaizzi's seven-step method was used for analyzing the data. In the first step, audio recordings were saved. Each written transcript was read multiple times by both authors. In the second step, important statements about the parents' experiences were determined from among transcripts. In the third step, significant expressions were formulated. In the fourth step, the formulated meanings reflecting the experiences of the parents were grouped into clusters of three common themes. In the fifth step, the basic structure was defined for the experiences of parents. In the final step, the findings were confirmed by contacting the participants again (Colaizzi, 1978). MAXQDA was used for coding and creating themes.

SPSS 22.0 statistical package program was used in the analysis of quantitative data. The Friedman Test was used to evaluate the difference between the pre-test and post-test total score averages of the Questionnaire for Determining the Needs of Children with BTM, and the Wilcoxon Test was used to determine which group caused the difference that was determined with the Friedman test. The significance level was accepted as $p < .05$.

2.6. Truthfulness

In qualitative research, the criteria used for ensuring the reliability of the research results are reliability, verifiability and transferability (Speziale et al., 2011, pp.222). To ensure reliability, researchers read and classified the transcripts multiple times and independently. To increase the reliability of the data, the authenticity of the data was maintained. In addition, after the transcripts were created, the participants were interviewed again and they were asked whether there were any statements they wanted to add or remove. To ensure reliability, all transcripts were reviewed by an expert experienced in qualitative research and familiar with the subject of the study. The responses of the children were conveyed in their original forms to ensure accuracy.

3. RESULTS

3.1. Demographics

The average age of the cases in the study is 15.46 ± 0.42. The descriptive characteristics of the children are shown in Table 1.

Table 1: Descriptive characteristics of the children (n=15)

Descriptive characteristics	Number	Percent (%)
Gender		
Female	7	46.7
Male	8	53.3
Children education level		
Primary School	5	33.3
High School	10	66.7
Where have you resided for most of your life (2/3)?		
Province	6	40.0
District	7	46.7
Village	2	13.3
Weight percentile		
<%3	8	53.3
%3 -%10	4	26.7

%10 - %90*	3	20.0
Height percentile		
<%3	4	26.7
%3 -%10	6	40.0
%10 - %50**	5	33.3
Maternal education level		
Illiterate	2	13.3
Literate	2	13.3
Primary School	10	66.7
High School	1	6.7
Maternal employment status		
Working in a regular income job	1	6.7
Working in an irregular income job	2	13.3
Not working	12	80.0
Paternal education level		
Illiterate	10	66.7
Literate	4	26.7
High School	1	6.6
Paternal employment status		
Working in a regular income job	7	46.7
Working in an irregular income job	8	53.3
Income Status		
Income is less than expenses	7	46.7
Income is equal to expenses	6	40.0
Income is greater than expenses	2	13.3
Frequency of erythrocyte transfusion		
1 in 3 weeks	11	73.3
1 in 4 weeks	4	26.7
Supportive treatment		
No	3	20.0
Folbiol + B vit.	1	6.6
Folbiol + zinc	6	40.0
Folbiol+zinc+ D vit.	4	26.7
Folbiol + zinc + D vit. +B vit.	1	6.7

* The highest weight percentile value among the subjects included in the study

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3.2.Content Analysis Results

In the interviews with the children included in the study, three themes were obtained regarding the medical process, family experiences and social life. These themes and sub-themes are explained below using quotations selected from the interviews.

3.2.1. Theme 1: Medical Process

The first main theme of the study, the "Medical process", reflects how the cases are affected by seven sub codes on BTM (Figure 1).

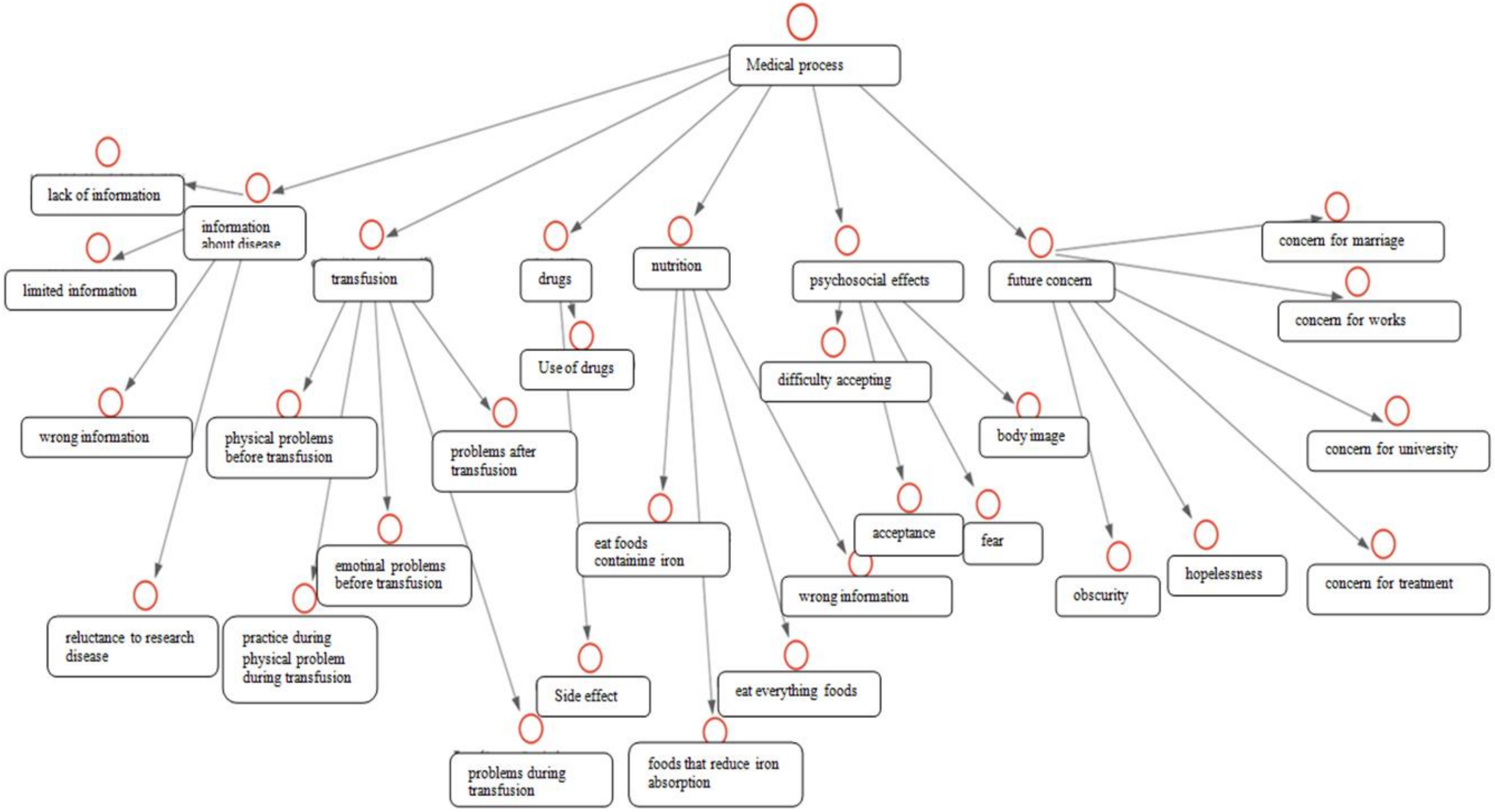

Figure 1. Medical Process Code-Sub Code Map

Many of children lack information about the disease. One of the children said: *"When I was little, they made me drink blood medicine, so I guess my iron increased, and this anemia occurred when the iron increased. It was a coincidence after all… "* (C12) Another child said: *"I have a little brother and an older brother. They do not have the disease, only I have, because I was born last. It coincided to me. Because I was the last child… It makes me sorry."* (C13)
Almost all of the children experience problems before erythrocyte transfusion.

"I feel exhausted too much. I had many headaches, of course, it happened on times close to blood transfusion. I am very well in the week following the transfusion, and feel exhausted in the remaining two weeks. I get bad until I was given blood again… " (C8)
12 of the children do not use their medication regularly.

"Actually I don't know much. For example, this disease can cause some problems. I have to use my medication regularly, but I cannot use it. I know my spleen and liver can get larger, but I don't know anything else. " (C3)

3.2.2. Theme 2: Family experiences

In the theme of the family experiences, the children's expressions about their relation with parents, relations with siblings, emotional process within the family, and how their transportation to the hospital affects their lives (Figure 2).

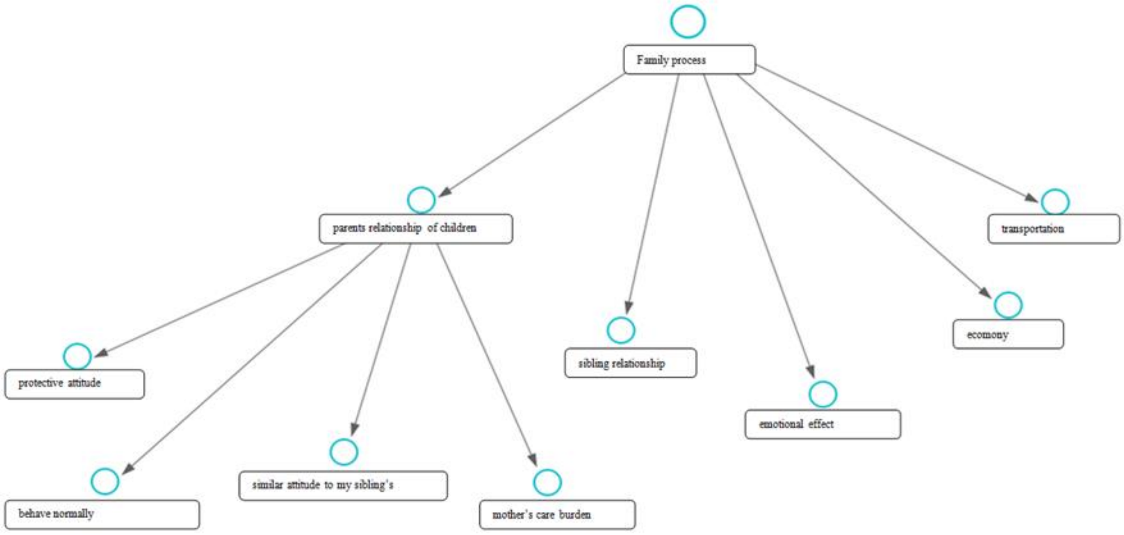

Figure 2. Family Experiences Code-Sub Code Map

The children said that their family had a protective approach.

"My mother is always next to me, and watching over me. For this reason, she does not want to let me stay away from her, always wants to be near me, and sometimes does not trust anyone. He does not even trust me. Because of this *she does not allow me to do anything and wants me near her all the time ... "* (C4)

Children used expressions stating that their families had economic difficulties and problems with transportation to the hospital. One child said:*"Coming here affects us* *financially. Because we always come and return, we travel with two people. For example, my mother cannot come, I come and return with my father, we hardly afford it economically, after all, my family are farmers."* (C12). Another child said: *"We get too tired, for example, we have to wake up too early to come here. We get up at five a.m. not to be late for the appointment. Sometimes it ends late, and sometimes early. It depends on the blood. We travel by bus. So it gets tiring. I am a little sleepless now, but I cannot sleep. I mean, if it is too tiring, I get a headache ... "* (C15).

3.2.3. Theme 3: Social life

This main theme consists of statements grouped under six sub-codes that indicate how BTM affects social life (Figure 3).

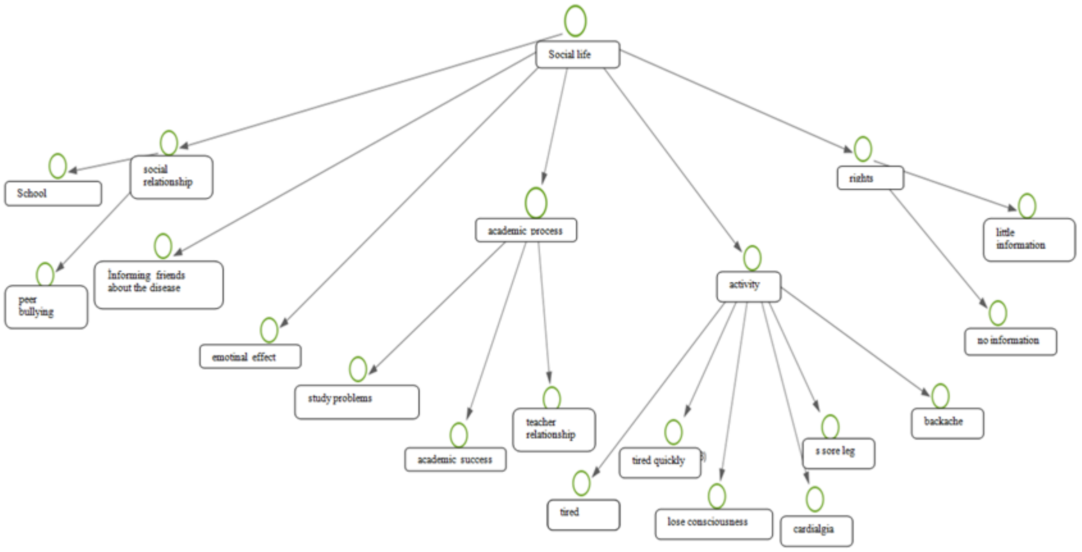

Figure 3. Social Life Code-Sub Code Map

Almost half of the children stated that they were exposed to peer bullying in their social relationships.

"I can't get along with anyone in the class because I am "preppy"". My friends do not make friendship with me because of my height. They are calling me "ant…" They are shouting at me "tall just as an ant." (C2)

All of the children used expressions stating that they had academic difficulties and that their school success was negatively affected.

"When I come here, I don't go to school. I cannot attend classes at that time; sometimes I cannot learn the subjects. If this disease had not happened… I would be more successful at school. I would be good at sports, and my scores in all lessons would improve. " (C13)

The children stated that they experienced fatigue (3/15), fatigue easily (5/15), heart pain (2/15), leg pain (2/15) and back pain (1/15) during physical activity. One child said:

"I had difficulty at physical education lessons, we run. Suddenly it feels like something was stabbed into my heart since I cannot breathe well. It hurts a lot. When I run, I cannot breathe, I get short of breath." (C2).

3.3. Children's individualized empowerment education

The total average score of children for the pre-test needs determination questionnaire was 30.73±2.38 (min.13; max.43), the first post-test applied after the education was 48±3.50 (min.38;max.52) and the second post-test was 47.86±3.52 (min.38; max.52).

A statistically significant difference was found between the total mean scores of the empowerment education pre-test, first post-test (after education), and second post-test (one month after the education) (X_2=26.00, p <.001). In the analysis performed to determine which group this difference originated from (Wilcoxon Test), a difference was found between the pre-education first post-test (z=-3.409, p=0.001) and pre-education second post-test (z=-3.409, p=0.001). The distribution graph of empowerment education is shown in Figure 4.

Figure 4. Distribution graph of strengthening training pretest-posttest total scores according to participants

4. DISCUSSION

BTM affects the life functions of children negatively due to being a chronic disease, having erythrocyte transfusion every three weeks, the complication of medical follow-up and care process, complications that may occur, and changes in body appearance. This situation reveals the needs in physiological, psychological and social fields (Ceylan et al., 2018,pp.15-

22; Roghani et al., 2018, pp.64-67; Hakeem et al., 2018, pp.1-9; Mansoor et al., 2018pp.211-214; Chong et al., 2019, pp.15-20; Shafie et al., 2020, pp.1-11).

Although the findings of the qualitative study are not generalized, this study is very important in terms of providing the opportunity to gain more and deeper information about the knowledge level of children with BTM of disease, of erythrocyte transfusion, of medicines and definitive treatment during the treatment process. In the part of the study regarding the treatment process, it has been revealed that children with BTM do not have information about the genetic transition of the disease. In the study by Hossain et al. (2020), it was found that of the children were lack of knowledge about the risk factor, the complications, and the Hb level for transfusion. This result reveals the importance of providing educational materials for children with BTM.

As in other chronic diseases, the care burden is mostly on mothers in BTM. Children between the ages of 12-18 receive support from their mothers in all areas of their lives, especially the treatment and care process. In the study, although children with BTM defined family relationships as good, seven of the children stated that they were not satisfied with the overprotective behavior of their families (especially of mothers). Before the education, 10 cases accepted that it was the right behavior for children with BTM to be angry with their families due to the illness. However, after education, the number of cases with this attitude decreased to one. This result shows that empowerment education is effective in informing children about the family experience. In the study carried out by Mufti, Towel, and Cartwright (2015), children with BTM stated that their families were overprotective. In the study carried out by Kumar et al. (2019), it was emphasized that mothers with children with BTM need psychological and emotional support.In the study carried out by Shahraki-vahed et al. (2017), it was stated that mothers with children with BTM had stated that they had emotional problems due to the growth of their children, changes in their children’s body images and stigmatization of their children. One of the most important findings about transportation. Children coming from different regions stated that they had to leave their homes very early to go to the hospital, and that they got very tired and could not have enough sleep. Also, families from experiencing financial difficulties. Although the treatment of BTM is free and a daylong in our country, families have to allocate a remarkable budget for transportation. In addition, children spend a day in the health unit for transfusion. Given that the families who took part in the study were not in a good financial situation, transportation costs and expenses during the day create an additional burden on their financial conditions. In the literature as well, it was stated that children with BTM had financial difficulties due to transportation costs to the hospital (Shahraki-Vahed et al., 2017, pp.243-251; Shosha & Al Kalaldeh, 2018, pp. 9-20).

It was revealed that seven of the children in the study experienced peer bullying in their social lives. Children are stigmatized, ridiculed and excluded because of the typical appearance of BTM. In addition, it was revealed that children experienced social isolation due to BTM. These results of the study are similar to those in the literature (Kumar et al., 2019). The children stated that they could not go to school from time to time, they slept in class and they had difficulty in listening to the lesson. In addition, they cannot attend school approximately once every three weeks. There are many studies in the literature suggesting that thalassemia affects children's school success negatively (Chordiya et al., 2018, pp.978-983; Mansoor et al., 2018, pp.211-214; Hakeem et al., 2018, pp.1-9; Ismail et al., 2018, pp.353-357; Roghani et al., 2018, pp.64-67). In our study, children experience difficulties during sports and activities that require excessive effort. In the literature , TM negatively affects the physical health of children (Ceylan et al., 2018, pp.15-22; Hakeem et al., 2018, pp.1-9; Ismail et al., 2018, pp.353-357; Mansoor et al., 2018, pp.211-214; Roghani et al., 2018, pp.64-67). Physical activity and exercise are very important for children with BTM to strengthen their bones. The only point that needs to be considered here is to determine together with health professionals how often and in what form the sport will be done.

In this study, individual empowerment education was given to children with BTM in line with their needs. After the education, it was found that the knowledge level of children about disease, treatment process, family experiences and social life had increased. It is an important finding that the knowledge level of children was high four weeks after the individualized education given. The active participation of children in individualized education, the opportunity to ask questions whenever they want, and the opportunity to access education whenever they want are the most important factors that increase the effectiveness of education. Another important factor is that educational materials were provided to children in both written and digital form and are available 24 hours a day. There is no study in the literature, but studies are addressing a sub-dimension of children's needs. It has been stated that the education with children with thalassemia are effective in all areas of life such as children's quality of life, self-efficacy, anxiety and depression. Ceylan et al. (2018), emphasized in the study in which the physical, emotional, social and school success of children with BTM were examined that the quality of life, physical and psychosocial health total scores of children who received education from health professionals related to BTM were higher. It has been reported that children have fewer problems with emotional and social functionality.

4.1. Limitations

The limitations of the study are that some children gave short answers to the questions in one-to-one interviews with children between the ages of 12-18 in the sample group and the sample group was between 12-18 years old. Secondly, the study was conducted in a single center; therefore, it cannot be generalized.

5. CONCLUSION

In this study, children's disease knowledge, treatment process, relations with parents and social life needs are seen. It was determined by the post-test mean scores that individualized education given in line with these needs was effective in empowering children. Nurses actively play a role in empowering the child at every stage of care in line with family-centered care principles for the management of these negative symptoms and the positive progress of the disease process. It shows that the individualized empowerment education given to children has positive effects on children's knowledge of the disease, treatment process, mother/father relationship and social life needs.

6. REFERENCES

Aydınok, Y., Oymak, Y., Atabay, B., Aydoğan, G., Yeşilipek, A., Ünal, S., ... & Evim, M. S. (2018). A National Registry of Thalassemia in Turkey: demographic and disease characteristics of patients, achievements, and challenges in prevention. Turkish Journal of Hematology, 35(1), 12-18.

Ceylan, S. S., Çetinkaya, B., Karabudak, S. S., Becit, N., & Kahraman, S. (2018). Examining the factors affecting quality of life of children and adolescents with Beta-Thalassemia. Journal of Dr. Behcet Uz Children's Hospital, 8(1), 15-22.

Cheuk, D. K. L.,Mok, A. S. P., Lee, A. C. W., Chiang, A. K. S., Ha, S. Y., Lau, Y. L., &Chan, G. C. F. (2008). Quality of life in patients with transfusion-dependent thalassemia after hematopoietic SCT. Bone Marrow Transplantation, 42(5), 319.

Chong, L. T.,Chong, M. C., Tang, L. Y., Ramoo, V., Chui, P. L., &Hmwe, N. T. T. (2019). The relationship between psychological distress and religious practices and coping in malaysian parents of children with Thalassemia. Journal of Pediatric Nursing, 48, 15-20.

Chordiya, K.,Katewa, V., Sharma, P., Deopa, B., &Katewa, S. (2018). Quality of life (QoL) and the factors affecting it in transfusion-dependent thalassemic children. The Indian Journal of Pediatrics, 85(11), 978-983.

Colaizzi P. Psychological research as the phenomenologist views it. In: Valle RS, King M, editors. Existential phenomenological alternatives for psychology. NewYork: Oxford University Press;1978.

Erdoğan, S., Nahcivan, N., & Esin, M. N. (Eds.). (2014). Research in nursing: process, practice and critical. Nobel Booksore

Fergus, N. (2002). An overview of thalassemia for parents adopting internationally. International Adoption Health and Medicine, 5(1), 1-15.

Gharaibeh, H., Barqawi, M. A., Al-Awamreh, K., & Al Bashtawy, M. (2018). Clinical burdens of β-Thalassemia Major in affected children. Journal of pediatri chematology/oncology, 40(3), 182-187.

Grewal N K.,Sodhi C, &Sobti P. (2017).To study the quality of life and its relation with socioeconomic status in thalassemic adolescents in a tertiary care center. CHRISMED Journal of Health and Research, 4, 33-37.

Hakeem, G. L. A.,Mousa, S. O., Moustafa, A. N., Mahgoob, M. H., & Hassan, E. E. (2018). Health-related quality of life in pediatric and adolescent patients with transfusion-dependent ß-thalassemia in upper Egypt (single center study). Health and Quality of Life Outcomes, 16(1), 59,1-9.

Hossain, M. S., Hasan, M. M., Raheem, E., Islam, M. S., Al Mosabbir, A., Petrou, M., ... & Siddiqee, M. H. (2020). Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: a cross-sectional baseline study. Orphanet journal of rare diseases, 15(1), 1-10.

Ismail, D. K., El-Tagui, M. H., Hussein, Z. A., Eid, M. A., & Aly, S. M. (2018). Evaluation of health-related quality of life and muscular strength in children with beta thalassemia major. Egyptian Journal of Medical Human Genetics, 19(4), 353-357.

Kumar, N., Turbitt, E., Biesecker, B. B., Miller, I. M., Cham, B., Smith, K. C., & Rimal, R. N. (2019). Managing the need to tell: Triggers and strategic disclosure of thalassemia major in Singapore. American Journal of Medical Genetics Part A, 179(5), 762-769.

Mansoor, S.,Othman, Z., Othman, A., &Husain, M. (2018). A descriptive study on quality of life among adolescents with beta-thalassemia major in themaldives. International Medical Journal, 25(4), 211-214.

Moghadam, M. P.,Nourisancho, H., Shahdadi, H., Shahraki, S., Azarkish, B., &Balouchi, A. (2016). Effects of home-care training on the self-efficacy of patients with beta thalassemia major. Materiasocio-medica, 28(5), 357-360.

Molazem, Z.,Noormohammadi, R., Dokouhaki, R., Zakerinia, M., &Bagheri, Z. (2016). The effects of nutrition, exercise, and a praying program on reducing ıron overload in patientswith beta-thalassemi amajor: A randomized clinical trial. Iranian Journal of Pediatrics, 26(5), 1-9.

Mufti, G. E. R.,Towell, T., &Cartwright, T. (2015). Pakistani children's experiences of growing up with beta-thalassemia major. Qualitative Health Research, 25(3), 386-396.

Origa R. (2017). β-Thalassemia. Gene Med, 19(6), 609-19.

Roghani, A.,Khan, N., Shah, I., Khan, S., Taj, A. S., &Yousafzai, Y. M., (2018). Quality of life and its determinants in transfusion dependent thalassemia. Pakistan Journal of Physiology, 14(3), 64-67.

Shafie, A. A., Chhabra, I. K., Wong, J. H. Y., Mohammed, N. S., Ibrahim, H. M., & Alias, H. (2020). Health-Related quality of life among children with transfusion-dependent thalassemia: a cross-sectional study in Malaysia. Health and quality of life outcomes, 18, 1-11.

Shahraki-vahed, A.,Firouzkouhi, M., Abdollahimohammad, A., &Ghalgaie, J. (2017). Lived experiences of Iranian parents of beta-thalassemia children. Journal of Multidisciplinary Healthcare, 10, 243-251.

Shamsi, A., Amiri, F., Ebadi, A., &Ghaderi, M. (2017). The effect of partnership care model on mental health of patients with thalassemia major. Depression Research and Treatment, 1-7.

Shosha, G. A, & Al Kalaldeh, M. (2018). Challenges of having a child with thalassaemia major: a phenomenological study. Journal of Research in Nursing, 23(1), 9-20.

Speziale, H., Streubert, H. & Carpenter, D. Qualitative research in nursing: Advancing the humanistic imperative. Lippincott Williams & Wilkins;2011.

Tarakmeh, T., Alaee Karahroudy, F., & Ghasemi, E. (2018). Evaluation of the Effect of Self-care Education on the Self-efficacy of Adolescents with Thalassemia Major. Scientific Journal of Nursing, Midwifery and Paramedical Faculty, 4(2), 59-70.

Zakiyah, I., Mediani, H. S., & Mardiah, W. (2018). Literature Review: Stress and Mother Life Quality with Thalassemia Children Major Ages 0–18 Years. Journal of Nursing Care, 1(3), 238-245.