



Coping behaviors in families with children suffering from thalassemia major and evaluating the implementation effect of nursing intervention on these behaviors

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ABSTRACT

Thalassemia disease in children, make the family and especially parents faced with many challenges. Better and more effective coping behaviors in father and mother, are followed by increased quality level of the sick child's life and the other family members. Therefore, the present study is conducted aims to evaluate the implementation effect of nursing intervention on coping behaviors of the families with children with Thalassemia major in Thalassemia Center of Doctor Mohammad Kermanshahi Hospital in Kermanshah at 2015. The research has been semi-experimental and the required information was collected through a 45-articles questionnaire of Maccubin called CHIP. The sample consisted of 38 families with children with Thalassemia major who admitted to the hospital of Doctor Mohammad Kermanshahi in Kermanshah that were selected by convenience sampling method in 2015. First, the coping behaviors of these families were determined and then divided into two groups of 19 individuals randomly that nursing intervention was implemented for 6 weeks in four sessions for each member of intervention group individually. Pre-intervention results indicated that the obtained scores in the first and third scales in each two groups is less than normal. Total post-test scores of coping behaviors in the control group have increased near to 1.05 units compared to the pre-test scores. But post-test scores of the families in the test group have increased near to 10.21 units compared to pre-test scores average. To compare the difference of pre-test and post-test scores between both control and test groups, independent t-test was used and based on the results of this test, a significant difference between two groups was observed ($P < 0.05$, $df = 36$, $t = -5.928$). So, the increase in the scores from pre-test to post-test in the test group was significantly higher. Thus, the implementation of intervention causes a significant increase in coping behaviors of families in the test group compared to the control group. According to the difference between the score average before and after implementation of nursing interventions in the test group compared to the control group, it can be said that implementation of nursing interventions is effective on the coping behaviors of families with children suffering from Thalassemia as well as these families need to strengthen their coping behaviors in the areas of first (maintaining social support) and third (improving social relationships) scales. And this issue needs the plan to implement nursing interventions for these families.

Keywords: Thalassemia major, nursing interventions, coping behaviors

INTRODUCTION

Thalassemia is the most common hereditary disease in the world [1]. Thalassemia major is the most severe form of beta thalassemia that person's life needs necessarily to receive regular blood transfusions and medical care [2]. About 3% of the world's population (150 million people) are only the carrier of beta Thalassemia gene, although

Thalassemia has been reported in more than 60 countries around the world, but the highest incidence of this disorder has been observed in malaria-prone belt of the world including Mediterranean countries, parts of the West and North of Africa, Middle East, subcontinent of India and South-East Asia. Also, Iran is a country located on the malaria-prone belt and faces with a relatively high prevalence of Thalassemia [3]. Mazandaram and Zanzan provinces have the highest with 2559 and lowest numbers with 58 individuals of people with disease, respectively [3]. Symptoms of the Thalassemia disease were indicated by Doctor Thomas Carey and his colleague Pearl Lee for the first time in 1952. Symptoms of Thalassemia major usually appear within the ages of 6 to 24 months that include delayed growth and puberty, enlarged liver and spleen, paleness, jaundice, impaired growth of the sex glands, sore feet, bone fracture and protruding of forehead, cheeks and jaws bones. In patients with beta Thalassemia major due to a very low level of hemoglobin, regular blood transfusions are required and it is tried to maintain the hemoglobin level of these patients between 9.5 – 10 g/dl. But, regular blood transfusions in these patients lead to iron accumulation in the vital organs such as liver, heart and endocrine glands and have some complications such as chronic liver hepatitis, cirrhosis, carcinoma, cardiac insufficiency, hypogonadism, hypothyroidism, diabetes and hypoparathyroidism[3]. Also, in Thalassemia major, skin disorders including rashes, scars, freckles, skin irritation or erythema due to the Desferal pump, hypomelanosis, fungal infections, contact dermatitis and acne are seen that the incidence of these symptoms increases with age [5]. Today, in spite of treatment which increases the life expectancy of these people, its clinical symptoms has still adversely effect on physical and psychological health of the patient and his family [6]. In case of children with chronic disease, parents are considered as the primary caregivers and thus will face with many challenges to comply with multiple and complex problems and tasks resulted from the child's disease [7]. Family cannot be imagined as the separated people and in fact it is a single unit. A unit that its people dependent on each other emotionally, physically and spiritually and they are affected from each other and affect on each other. Suffering of one will affect the others and all try to provide the best and most suitable conditions in all aspects for living together. If a member of the family is sick, parents will be affected by his disease and try to reduce his pain and provide happiness and success for him [8]. First reaction of many parents is shock and disbelief and it takes months to fully embrace the concept [9]. Results of a study in 2004 showed that 3.6% of families with patients with Thalassemia suffer from natural anxiety and 18.5%, 50% and 27% from mild, moderate and severe anxiety, respectively. In addition, results showed that 50% of family members suffered from severe depression and the above mentioned indicates that families with patients with Thalassemia are at Psychological-mental risks [10]. Thalassemia major is usually diagnosed when the child is a few months old. The pressure of having a child, who needs severe care and regular blood transfusions, will change the mental balance of parents for a while. This trauma to the family causes various psychological reactions in members and family relations will be affected seriously [11]. Finally with a brief summary of the studies, it can be found that Thalassemia has complications and many psychological-social and physical effects of the sick children, parents and other family members and these complications can affect on the quality of patient's life and his parents in many aspects [6]. In fact, these families may not have good coping behaviors. The behaviors and reactions of each person that may occur in adverse circumstances to balance and control the stress due to that event is called coping behavior. Also, these behaviors are more important in families with a sick child and should be strengthened. So, it is important that parents how deal with the critical situation which is occurred for their child as it shows their acceptance from their child condition and indicates how much ability they have to control and manage the situation of their sick child [12]. Also, Mccubin suggests that coping behavior includes individual and collective efforts (to help other people or programs) to manage associated confrontation with health problems in the family [13]. Better and more effective compliance will be followed by enhanced quality of sick child's life and other members of family. Knowledge of adaptive behaviors used by parents provides nurses with the possibility to design intervention programs for an appropriate support of them [14]. Any changes in human life including pleasant and unpleasant ones require a kind of readjustment. Coping methods with changes of life and tensions resulting from these changes are various in different people and depending on various situation. Coping strategies means a set of cognitive and behavioral efforts that is applied in order to interpret and correct a stressful situation and leads to alleviate suffering of it [15]. In case of using the effective coping styles, emotions are modulated and stress will be removed [16]. Effective coping is an important source to create a well-being feeling and psychological adjustment in stressful situations and affects on physical and psychological health of individuals. Effective coping styles reduce the negative effects of stress and the ability of management of environmental and internal stressors or development of these behaviors increases. While ineffective coping styles increase the negative effects of stress. Effective coping is an important source to create a well-being feeling and psychological adjustment in stressful situations and affects on physical and psychological health of individuals [17]. Families without an appropriate coping behavior do not provide enough supports for their sick child and it will have a negative effect on psychological health of children. Training plan aims to increase coping skills in families with children with Thalassemia can be useful in decrease of psychological problems in children.

MATERIALS AND METHODS

Convenience (easy) sampling method was used in this study. In this study, researcher selected 46 parents from 240 parents who accompanied their children to visit and were willing to cooperate after giving consent of them to study it. After the explanations provided by the researcher regarding the study and in the research atmosphere, 46 families were ready to participate in the study and then the consent letters were collected from the samples. In practice, 8 of parents were excluded from the study because of poor response and a number of questions remain empty as well as lack of willingness to cooperate that the study was performed on 38 people from the families and the selected 38 parents were divided into two groups of 19 people (test group and control group). In this study, Mccubin CHIP questionnaire was used before and after intervention for the parents. A questionnaire about personal and family information was attached to the mentioned questionnaire. CHIP questionnaire is a 45-points tool aims to assess parents' reaction in management of family life when a family has a child with acute or chronic disease. CHIP articles are made using the previous articles in the field of family stress and the theories of related areas to the family and health. As a result of cause's analysis, CHIP consists of 3 subscales: maintaining the integrity of family, cooperation and optimistic definition of the situation=> first scale.

Maintaining social support, self-esteem and psychological stability => second scale

Understanding of disease or health situation of the child through contact with other parents or consultation with doctors => third scale [18].

In time of filling the questionnaire, people studied the items of coping behaviors in each 3 subscales and showed that how far doing of each behavior is useful. Based on the obtained information from several studies which have used this tool, the researchers have provided normal scores as a method to compare [14].

Normal scores of adaptive patterns:

Sub group of behavior	Mean	SD	Domain
Family integrity and optimization status	40	15	25-55
Self-esteem, social support and psychological stability	28	12	16-40
Communication and medical advice	15	7	8-22

Total normal scores are not mentioned (19).

CHIP questionnaire has the criterion validity and construct validity. In addition, Cronbach's alpha test for a good internal consistency and for three factors and mentioned subscales were 0.79 and 0.71, respectively. This questionnaire has been translated to Spanish, Greek and the other languages. The Persian version of it from the book "the assessment tool of couples, family and children", which is extracted from the pages 170-174, was used in this study. CHIP has a relative validity by solidarity with some scales of family. Also, it has a well-known group validity and the ability of distinction between high conflict and low conflict families [18].

Mccubin et al obtained Cronbach's alpha to measure internal consistency of the tool during two separate studies as 0.79 and 0.71 [19].

Coping behaviors of the samples before intervention was measured and recorded by the mentioned questionnaire at first. According to pre-test results, ineffective coping behaviors in the studied unit was identified. Then, based on the obtained results, nursing interventions were designed and implemented. These interventions took time for 6 weeks. After 6-weeks interventions, CHIP questionnaire was given to both test and control groups again. Given that the majority of visitors visited Thalassemia Center twice a month, there were totally 4 of 2-hours sessions to intervene for each sample. According to the results, these families were affected in the first and third scales and the obtained scores in the second scale were normal. So, the provided training packages and CDs included the following topics:

- 1- The ways to control stress
- 2- Improvement of social relationships

Based on the intervention plan, in each session we discussed with these families regarding expression of their feelings and unsolved problems which were usually occurred in their life. Then, the researcher tried to change these families' approach regarding problems with the advice of medical sense. It is necessary to explain that patients did not visit simultaneously in a particular day and researcher went to the Thalassemia center by having their plan of visit and paid interventions separately for the family of patients. After the end of each counseling session, the researcher gave them the training packages and CDs that they studied them till the next visit and asked their questions at the beginning of the next session to receive their responses.

RESULTS

The related results to the individual and family characteristics of the families showed that 63.2% of the studied units were in the control group and 68.4% were at the test group of mothers with children with Thalassemia and distribution of parents in both groups were similar and no significant difference was seen in both test and control groups in terms of average age of father, mother's age, father's education, mother's education, father's occupation, mother's occupation, marital status of parents, consanguinity, chronic disease of parents, history of hospitalization of parents, chronic diseases in other children of the family and Thalassemia in other children of the family. Also, Mann-Whitney test result do not show a significant difference between both test and control groups in terms of child birth, age of diagnosis, age of beginning the disease, the numbers of blood units transfused, family size and age of the child with Thalassemia and based on the result of Chi-square test, no significant difference was seen between both groups in terms of location and sex of children with Thalassemia. In the first area (maintaining the family integrity, cooperation and optimistic definition of the situation) and the third area (understanding of disease or health situation of the child through relationship with other parents or consulting with doctors), the obtained scores before intervention in both test and intervention groups were less than normal.

The mean and standard deviation of the scores of the studied units from the coping behaviors in the area of family integrity, cooperation and optimistic definition of the situation before and after intervention in both test and control groups

	Before intervention		After intervention		P-value
	Mean	SD	Mean	SD	
Test	35.11	4.79	40.63	3.82	<.001
Control	35.53	6.13	36.47	4.87	.098
p-value	0.815		0.006		

The average of difference of pre-test and post-test scores from the coping behaviors in the area of family integrity, cooperation and optimistic definition of the situation before and after intervention in both test and control groups

	Mean	SD	Test statistics	Degree of freedom	P-value
Control	.95	2.37	-5.255	36	<.001
Test	5.53	2.97			

Based on these results in the control group, the scores in the area of maintaining family integration in post-test have increased an average of 0.95 unit compared to the pre-test scores but in the test group, pre-test scores of the families have increased an average of 5.53 units. To compare the difference between pre-test and post-test scores between two control and test groups, independent t-test was used and according to the results of this test, a significant difference was observed between two groups ($P < 0.05$, $df = 36$, $t = -5.255$). So, increase rate of the scores from pre-test to post-test in the test group was significantly higher. Thus, intervention causes a significant increase in the coping behaviors of the families in the area of maintaining family integration in the test group compared to the control group.

The mean and standard deviation of the scores of the studied units from the coping behaviors in the area of understanding of disease or health situation of the child through relationship with the other parents or consulting with doctors in both test and control groups

	Before intervention		After intervention		P-value
	Mean	SD	Mean	SD	
Test	13.11	2.31	15.63	2.36	<.001
Control	11.95	2.17	12.21	1.90	.098
p-value	0.120		<.001		

The average of difference of pre-test and post-test scores from the coping behaviors in the area of understanding of disease or health situation of the child through relationship with the other parents or consulting with doctors in both test and control groups

	Mean	SD	Test statistics	Degree of freedom	P-value
Control	.26	1.37	-3.947	36	<.001
Test	2.53	2.09			

According to the results, in the control group the scores in the area of understanding the disease or health situation of the child in post-test have increased an average of 0.26 unit compared to the pre-test scores. But in the test group, pre-test scores of the families have increased an average of 2.53 units compared to the average of pre-test scores. To

compare the difference between pre-test and post-test scores between two control and test groups, independent t-test was used and according to the results of this test, a significant difference was observed between two groups ($P < 0.05$, $df = 36$, $t = -3.947$). So, increase rate of the scores from pre-test to post-test in the test group was significantly higher. Thus, implementation of the intervention causes a significant increase in the coping behaviors of the families in the area of understanding the disease or health situation of the child in the test group compared to the control group.

DISCUSSION AND CONCLUSION

In general, the results of this study showed that families with children with Thalassemia major have been damaged in the area of maintaining the family integration and relationship and medical advice and need to strengthen the coping behaviors in these areas. Also, the results showed that implementation of the nursing interventions has a significant relationship with the increase of coping behaviors in families with children with thalassemia major. In this study, in spite of implementation of interventions in the first and third areas, the scores average of coping behaviors in the second area and the average of total scores increased significantly. Since, inappropriate coping behaviors causes psychological-mental problems in parents and following them, in their children, the necessity of implementation of nursing interventions in this field and doing the individual and group consulting of parents seem absolutely necessary. Nurses and other caregivers in the health-treatment team should focus on the programs and intervention which can improve the coping behaviors of parents with children with thalassemia and or other chronic diseases and use these programs in care planning for these patients. The results of this study was in consistent with the results of Aqajani et al study entitled with evaluating the effect of spiritual consulting on anxiety and depression in hemodialysis patients which was conducted on 90 patients with chronic renal disease in Amin Hospital of Isfahan in 2013. According to this research, spiritual consulting can cause a decrease in anxiety and depression in dialysis patients (20). Also, it is in consistent with the study of Enadi et al as the effect of education on the anxiety of mothers with children suffering from urinary infections that was performed on 40 individuals of mothers with hospitalized children in Qods Hospital of Qazvin in 2014 that based on that, education is effective on the manifest anxiety but had no effect on the hidden anxiety (no effect on the hidden anxiety can be attributed to the fact that the nature of disease is not chronic [21] and these results were in consistent with the results of Roseland . This research has stated that participation and current cooperation of the people and friends in person in the life of patients with chronic disease and their families cause an increase in social support and improvement of their self-confidence [22] and is consistent with the research of HemmatiMaslak Pak et al entitled with evaluating the effect of implementation of self-care program on the self-esteem of the elderly people who live in the nursing homes of Urmia in 2012 that based on it, implementation of self-care program has a positive effect in increase of self-esteem of the elderly people [23] as well as Lavasani et al study with the title of the educational effect of social skills on the social adjustment and educational function late-to-learn students in Zanjan province which was conducted in 2010. That according to the intervention plan has had a significant effect on improvement of social adjustment and educational function of late-to-learn student boys in the test group (24). Also, it corresponds to the results of Sheqaqi which it was shown on that study that holding of family educational classes had been effective on the health of parents with mentally retarded children and improves the level of physical disorders and anxiety and public depression and health [25].

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