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Research Article

The Effect of Partnership Care Model on Anxiety of Adolescent with β-Thalassemia

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Background: Beta-thalassemia major (TM) is a chronic, genetically determined hematological disorder and affects different aspects of patient's psychological life.
Objectives: This study was designed to examine the impact of partnership care model on anxiety of adolescent with β-thalassemia in 2013.
Materials and Methods: This quasi-experimental study was performed by selecting 60 adolescent with β-thalassemia. Patients were randomly allocated into two groups of tests and control groups (each group included 30 patients) in Shahid Dastgheyb Hospital of Shiraz. The partnership care model, which consisted of four main steps of orientation, sensitization, control and evaluation, was performed for the experimental group. Data collection tool was Depression Anxiety Stress Scale (DASS-21) questionnaire that assessed adolescents' anxiety before and after 3 months, which was completed by both groups. The data were analyzed using SPSS v.16 by chi-square test, paired T-test and independent T-test.
Results: Analysis showed that there was no significant difference between the test and control groups in terms of demographic characteristics ($P > 0.05$). Also, There was no significant difference in anxiety score between two groups before intervention ($P = 0.81$). But significant difference was seen between two groups after intervention using independent T-test ($P = 0.001$). Pair T-test showed a significant difference in the anxiety reduction in the test group after the intervention ($P = 0.001$), whereas the same test showed no significant difference in the control group ($P = 0.30$).
Conclusions: Applying partnership care model can reduce level of anxiety in adolescent with β-thalassemia. Therefore, it is recommended to use this model to reduce anxiety in adolescent with β-thalassemia and adolescents with chronic diseases.

Keywords: β-thalassemia; Anxiety; Adolescent

1. Background

Thalassemia is a common genetic blood disorder, characterized by reduction of specific globin chain of hemoglobin and its most common type is beta thalassemia (1). Thalassemia includes a wide range of clinical and psychological challenges and can lead to physical deformities, growth retardation and delayed puberty. Furthermore, thalassemic adolescents feel different from their peers and elaborate negative thoughts about their life, guilt senses, increased anxiety and low self-esteem (2). There are about three million carriers of the faulty gene and also about 25 thousand people diagnosed with major thalassemia in Iran. The highest incidence rate is observed in the Caspian Sea and Persian Gulf coasts (3). Thalassemia is very abundant throughout the country, where 10 percent of the population of the Caspian sea and southern coast's and four to eight percent of people in other areas are carriers of thalassemia gene (4). Thalassemia major, like any other chronic disease, affects every aspect of patients' life. Despite medical therapy, its symptoms and clinical manifestations cause the patient to face with stress, anxiety and depression. Continuous phlebotomy required for testing, constant injections of blood derivate and repeated subcutaneous injections of iron chelators drugs put these patients at risk for mood disorders such as anxiety (5). In many patients with thalassemia, the disease can affect other aspects of life. Researches shows that 80% of patients with thalassemia have at least one psychiatric disorder (6).

Adolescence is a sensitive period in life even for healthy people. Studies have shown that adolescents with a chronic disease are at higher risk of psychological and social problems and anxiety, compared to their healthy peers. Problems in adolescents with chronic diseases include unpleasant mental image, fear of rejection, anxiety, peer relationship problems, fear of independence and low self-sufficiency, which can alter their self-concept (7). Pourmovahed et al. found that thalassemic patients have difficulties passing through the stage of puberty and adolescence and their psychological, social and biological aspects are affected (8). Adolescence is an important stage of social and psychological development (9). Frequent absences from school, decreased academic performance, low self-esteem, feeling desperate caused by dependence on others for care, feeling incompetent to perform certain routines, anger, feeling anxious when facing uncertain and unknown situations, grief due to loss of health and lack of independence, limitations in social communication, fear of premature death, and the idea that their lives are different from that of others adversely affect their morale and psychological conditions (10). Gholizadeh showed that mean scores of anxiety, depression, aggression and timidity in thalassemic patients were higher than those of healthy controls (5). Limitations in social activities, fear, pain and anxiety associated with diagnostic procedures that are always stressful for thalassemic patients, are sources of anxiety (11). Goldbec et al. showed that most patients feel mentally-disordered due to repeated treatments. This is due to maladaptive strategies for dealing with the disease and its treatment. They stressed the need for continued support in these patients (12). Nevertheless, nursing models can be good guides for improving quality of care; thus, this study used an indigenous model called "partnership care model" for adolescents with thalassemia and evaluated its efficacy in reducing anxiety in these patients. Partnership care model (PCM) was first designed by Mohammadi et al. in 2002 and was used to control hypertension in Babol (13). This model includes four scales of orientation, sensitization, control and evaluation. This model introduces patient as a factor affecting the health care and follow-up process. Continuous or ongoing care is a regular process for effective communication and interaction between patients and nurses - as a health care provider - to identify the patients' needs and problems and sensitize them to continuous health behaviors and improvement of their health. Due to chronic and debilitating nature of chronic diseases such as thalassemia major in children and adolescents, the dynamic and changing mental health problems in these patients and the fact that most of these patients in our country are in the age group below 18, these diseases exert a profound influence on the patient and the entire family and deplete all their resources. However, with recent developments, if a thalassemic adolescent is treated well, he or she can become a young adult with high potentials for social participation. Therefore, a study is needed to investigate these patients' participation in a collaborative program. Because adolescents are affected by each other, a peer-based role can be used to improve their psychological condition. There is a need for using a model that fits these patients' conditions.

2. Objectives

The purpose of this study is to determine the effects of PCM on anxiety in adolescents with thalassemia major.

3. Materials and Methods

This is a quasi-experimental study to determine the effects of PCM on anxiety in adolescents with thalassemia major in Thalassemia Center of Shahid Dastgheyb Hospital of Shiraz. The study sample consisted of all adolescents with thalassemia major who were members of the Thalassemia Center. The criteria for inclusion included being adolescents 11 to 18 years, being diagnosed with thalassemia major and receiving blood regularly. Exclusion criteria include failure to complete the follow-up period, diagnosis with another chronic illness, severe physical complications as well as the inability to complete the questionnaire. Sample size estimation estimate was based on a similar study by Khoshab (14). Using anxiety mean difference and Pocock method with 80% confidence and 95% power, a sample size of 21 was determined. Due to the risk of loss to follow-up, 60 patients (30 in the control group and 30 in the experimental group) participated in the study. First, convenient consecutive sampling was used to select subjects; then randomized allocation to the experimental and control groups was performed. Patients who referred on odd days were assigned to the experimental group and those referred on even days were assigned to the control group. For ease of learning and program effectiveness, the intervention group was assigned to two groups (n = 15 in each group). Next, PCM was done on experimental group. The first stage, orientation, was carried out during two sessions, each 90 minutes. This stage included review and identification of actual and potential problems of adolescents with thalassemia. The assessment led to a problem list including lack of awareness of the diet and experiment as the first axis; ignorance towards health-centered behaviors, including stress management, physical activity, interpersonal relationships and psychological problems as the second axis; and the inability to control psychological problems and problems with self-esteem, self-efficacy and body image as the third axis of the disease effects. The next step included sensitization in order to encourage subjects to act properly and sessions of collaborative training visits and follow-up tasks with the presence of the patients, their family and caregivers. During two sessions of collaborative training, the subjects were trained about diet, the nature of the disease and treatment, and application of Benson relaxation techniques each two hours. Also, group discussions were held for each group on mental health issues and their impact on health-centered behaviors such as management-oriented stress, physical activity, responsibility, mental health, interpersonal relationships, perception of each other's experiences and sharing concerns. In the control stage, stress on receiving feedback on the results of the meetings and educational content presented in the collaboration training alongside to counseling, group discussion, lecture and question and answer sessions were held for each group. In two cases, the problems raised were outside the scope of expertise and knowledge of the researcher and the adolescents and families were referred to a psychologist. Given that the model used requires ongoing care and follow-up, the first and second stage lasted one month. It should be noted that most participants referred once every three weeks, but in order to implement PCM, they agreed to refer every week and the intervention was carried out for each group on a weekly basis. The researcher had a regular physical presence during program implementation (continuing care advice on a weekly basis, with face to face presence and phone calls depending on care needs; controlling the program through observation of checklist preceding muscles relaxation technique and reviewing test results). With the aim of finding new care problems (because of the dynamic nature of health and disease). Sensitization for new problems was carried out followed by quality control and follow-up measures. In the research process, the follow-up was done on a weekly basis and sometimes during each referral to the center via group sessions. In the end, to improve the effectiveness of the intervention, CDs containing preceding muscles relaxation techniques were given to the patients. Evaluation was carried out on stage basis at the beginning and end of each session. Data collection instruments included demographic checklists on age, gender, marital status, occupation, income, education level, disease history, candidate for bone marrow transplant and visit interval. Depression Anxiety Stress Scale (DASS-21) questionnaire was also used to measure stress, anxiety and depression in adolescents with thalassemia. In this study, the anxiety scale (seven items) was used. This is a Likert questionnaire with answers ranging from never, low, medium and high. The maximum and minimum scores of each question are three and zero, respectively. Anxiety level from zero to four is normal, five to 11 is medium and 12 to 21 is severe. Validity of the questionnaire has been confirmed in other studies (15). To assess the reliability of instruments in this study, test retest method was used. The questionnaires were administered two times within seven days interval to 20 adolescents with thalassemia. Then, the reliability was confirmed with an alpha Chronbach coefficient of 0.78. For ethical considerations, after obtaining permission from the research deputy of Shiraz University of Medical Sciences and presenting it to the Cooley's ward, informed consent from all patients were obtained and they were given assurance that their information will remain confidential. They were informed that they can reject participation in the study whenever they want, and can exclude themselves from the trial. The questionnaires were distributed by the researcher in frequent visits to the Cooley's ward at the appropriate time. The subjects answered the questionnaires without direct supervision of the researcher. Then the questionnaires were collected at once by the researcher. In general, DASS-21 questionnaire was administered twice (before and three months after intervention) to the subjects in both experimental and control groups. The data were analyzed using chi-square test, independent sample t-test and paired t-test. P values less than 5% was considered statistically significant.

4. Results

The number of participants in this study for both intervention and control group was 30 subjects without exclusion till the end of the study. The mean and standard deviation age of the adolescents in the intervention group was 15.23 ± 2.44 years and in the control group was 15.7 ± 2.26 years. In the control group, 15 patients (50%) and in the intervention group 12 patients (40%) were male. In the control group, 46.7% and in the intervention group 60% were referring to the Thalassemia Center once every two weeks. Demographic and disease-related data are given in Table 1. The two groups had no significant difference in terms of variables such as age, gender, education, frequency of referral and being candidate for bone marrow transplant and splenectomy. Independent t-test showed no significant differences between the mean anxiety score of the two groups before the study (P = 0.25). After three months, there was a significant difference between the mean anxiety scores of the experimental and control groups after the intervention (P = 0.001). Paired T-test showed a significant difference between the mean anxiety scores of the intervention group before and after intervention (P = 0.001). The same test showed no significant difference in mean anxiety scores of the control groups before and after intervention (P = 0.30) (Table 2). Findings also showed that 66.7% of adolescents in the intervention group had moderate to severe anxiety before intervention that decreased to 40% after the intervention (Table 3).

Table 1. Demographic Characteristics of the Two Groups of Patients [a]

Variable	Control		Intervention		P Value
Gender					0.43
Female	15	50	18	60	
Male	15	50	12	40	
Age					0.78
11-14	9	30	10	33.3	
15-18	21	70	20	66.7	
Education					0.99
Below diploma	25	83.3	25	83.3	
Diploma	5	16.7	5	16.7	
Number of times referred					0.51
Every two weeks	14	46.7	18	60	
Every three weeks	12	40	10	33.3	
Every four weeks	4	13.3	2	6.7	
Bone marrow transplant candidate					0.68
Yes	4	13.3	3	10	
No	26	86.7	27	90	
Splenectomy					0.64
Yes	2	6.7	3	10	
No	28	93.3	27	90	

[a] Values are presented as No. and percent.

Table 2. The Anxiety Mean Score and SD in the Two Groups Before and After Intervention

	Before [a]	After [a]	P Value
Control	7.70 (2.53)	7.13 (2.80)	0.30
intervention	8.80 (2.24)	5.03 (1.99)	0.001
P Value	0.25	0.001	P

[a] Mean ± SD.

Table 3. Relative and Absolute Frequency of Adolescents with Thalassemia According to the Level of Anxiety in Two Groups Before and After Intervention

Anxiety score	Control				Intervention			
	Before		After		Before		After	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
Normal (0-4)	17	56.7	12	40	10	33.3	18	60
Moderate (5-11)	13	43.3	16	53.3	17	56.7	11	36.7
Severe (12-21)	0	0	2	6.7	3	10	1	3.3
Total	30	100	30	100	30	100	30	100

5. Discussion

In this study, the impact of PCM on anxiety in adolescents with beta-thalassemia major was studied. The results showed that PCM make a significant difference between anxiety scores of the intervention and control groups after the intervention. This is while the mean anxiety score of the two groups showed no significant difference before intervention. These results demonstrate the effectiveness of the PCM in reducing anxiety in adolescents with thalassemia major. In other words, there was a small difference between mean anxiety scores in the two groups before the intervention, but this difference was statistically significant after the intervention. Alijany et al. studied impact of PCM conducted on quality of life of children with thalassemia; results showed a significant improvement in their quality of life after three months of intervention (16). Also Khoshab et al. studied the effects of a PCM on anxiety and depression in patients with heart failure, result showed the significant effects of partnership care on reduction of depression and anxiety in patients with heart failure (14). Sullivan et al. in a study was conducted on patients with anxiety disorders in order to investigation the impact of an innovative model of partnership care in treating anxiety disorders among these patients; the results showed improvement in the level of anxiety in the intervention group than in the control group (17). These results are in accordant with those of Mohammadi et al. entitled a Partnership care model for evaluation of hypertension in Iran (18). Adolescents are more dependent upon relationships with peers than to children. Because the bond with parents is weakened in this period and seek independence, their social behavior and cultural values are challenging. An adolescent ridiculed or ignored by peers will become anxious. Adolescence is generally a time of socialization and at the same time is a period when he/she feels more alone (19). Therefore, the PCM focused on group discussions and interviews with peers and counterparts can have desirable effects on reducing anxiety and emotional tension in adolescents, especially those with chronic diseases. In the present study, findings showed that 66.7% of adolescents in the intervention group had moderate to severe anxiety before intervention, which decreased to 40% after the intervention. This shows the effectiveness of the PCM in reducing anxiety in adolescents with beta-thalassemia major. This is in line with results of Khoshab et al. study on the impact of PCM in reduction of elderly depression and on the psychological dimension of quality of life of adolescents with thalassemia (14). Because the mental image, self-esteem and self-efficacy are formed and are increasing in adolescence, in this study, the researcher tried to improve the subjects' self-esteem and reduce their anxiety via group training, active participation and interaction with team members in group discussions to share experiences with each other. It should be noted that desired body image is related to untimely or delayed sexual maturity and the adolescents' attention to their appearance affects their self-esteem and mental health (20). In this regard, the study by Ermes et al. introduced participatory approach and group discussion as effective method in reducing depressive symptoms and anxiety and improving self-esteem and it is considered as an efficient non-drug method for enhancing self-esteem and improving the positive self-image (21). Anxiety, fear and concerns are important factors that reduce self-esteem followed by severe anxiety. Therefore, in the present study, peer group discussion sessions were important elements in reducing anxiety in adolescents. These results are in accord with Ermes et al. research (21). Findings of Gholami et al. research that studied the effectiveness of group training program on life expectancy and public competence of girls 15 to 18 years suffering from beta-thalassemia showed that life expectancy and general health increased of the girls (22). Also, in a study by Moghadasi et al. who investigate the effect of group discussion on body image among thalassemic adolescents, showed significant improvement of self-psychological and self-adaptation dimensions and using participatory methods improved the mental image and reduced anxiety in adolescents with thalassemia (23). The critical period of adolescence is the time of formation of identity, self-esteem and positive self-concept and the emotional condition of adolescents depends on their interactions with others, especially peers. Therefore, the model used in this study relies on continuous, dynamic and effective relations that adapted to the chronic disease properties and problems. The results indicate the positive impact of this model to improve the level of anxiety in adolescents with thalassemia. Therefore, the PCM with its information exchange properties and its requirement for continuous presence of subjects and formation of support groups can have positive effects on reducing anxiety in adolescents, especially those with chronic diseases. In the present study, because of participatory nature and dynamism of the PMC, the results confirm the effectiveness of the model in reducing anxiety of adolescents with thalassemia. Yang et al. concluded in a study in Taiwan that having awareness about thalassemia and its complications and social support was positively associated with self-care in these patients. Friends are the least and family is the most important social resource for thalassemic adolescents (24). In spite of this fact, health professionals have not been paying enough attention to the educational role of community and family for thalassemic patients. Regarding to this gap and the importance of family in protecting adolescents, such collaborative programs produce good results that can help health care providers in developing better policies using this approach.

It should be noted that limitations of this study include personality type, low sample size, effects of personality characteristics on the acceptance of training method and self-care responsibilities as well as mental conditions of subjects in training sessions , which could not be completely controlled by the researchers; therefore, the results should be generalized with caution. Our findings indicate the effectiveness of PCM in reducing the level of anxiety in adolescents with beta-thalassemia major. Regarding to the fact that the prevalence of anxiety in patients with chronic diseases is much higher than that in ordinary people, and also due to the effectiveness of the model and its affordability and ease of use for families and adolescents, treatment centers and care providers of these patients are recommended to benefit from the impact of this model on reducing anxiety in adolescents with thalassemia and other chronic diseases. In this regard, it is recommended that future studies use collaborative training approach with participation of other health care staff and counselors in training so that better programs are identified for health promotion and managing complications in adolescents with thalassemia in families and society.

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