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# **ORIGINAL PAPER**

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# EFFECTS OF HOME-CARE TRAINING ON THE SELF-EFFICACY OF PATIENTS WITH BETA THALASSEMIA MAJOR

# Mahdieh Poodineh Moghadam<sup>1</sup>, Hajar Nourisancho<sup>1, 2</sup>, Hossein Shahdadi<sup>1</sup>, Sohila Shahraki<sup>2</sup>, Batoul Azarkish<sup>2</sup>, and Abbas Balouchi<sup>2</sup>

<sup>1</sup>Department of Nursing, School of Nursing and Midwifery, Zabol University of Medical Sciences, Zabol, Iran <sup>2</sup>Student Research Committee, Faculty of Nursing and Midwifery, Zabol University of Medical Sciences, Zabol, Iran

Corresponding author: Hossein Shahdadi , Department of Nursing, School of Nursing and Midwifery, Zabol University of Medical Sciences, Zabol, Iran. E-mail: hosienshahdadi@gmail.com

## ABSTRACT

Background: The self-efficacy of thalassemia patients is an important factor in creating behavioral changes in such patients. Home-care training reduces hospitalization duration as well as relevant costs and improves disease outcomes. This study was designed to assess the effect of home-care training on the self-efficacy of patients with beta thalassemia major. Methodology: This was a quasi-experimental, case-control, before and after intervention study conducted on 136 thalassemia cases from January 2014 to October 2015. Data was collected through Shere general self-efficacy questionnaire (SGSES). Home-care trainings were provided in the form of training courses with respect to the training needs of thalassemia major cases. Two (2) months after the end of training courses, SGSES questionnaire was filled again and the obtained data was analyzed by SPSS 21 as well as descriptive-inferential statistics (significance level=P≤0.05). Results: The results of this study revealed that the mean self-efficacy score of control group was 48.69±6.82 before intervention which increased to 46.69±6.81 after intervention. The mean self-efficacy score of case group was 44.58±5.23 before intervention which increased to 49.5±6.66 after intervention. The rise of self-efficacy score, after intervention, was significantly higher in the case group compared with the control group (P≤.001). Conclusion: According to results, home-care training can develop self-efficacy in thalassemia patients. In home-care training procedure patients play an active role. By providing home-care trainings, therefore, an effective step should be taken to promote the self-efficacy of the patients and to decrease associated problems.

Key words: Home-Care Training; Self-Efficacy; Thalassemia Major; Patients.

## **1. INTRODUCTION**

Thalassemia is a congenital inherited hemolytic disease with different minor to majeure incidences (1). According to global statistics, 5% of people of Mediterranean and Southeast Asia countries are the carriers of thalassemia gene (2). Iran lies inside thalassemia belt (3) so that 10% of people living in Caspian Sea margins and southern Iran are the carriers of thalassemia gene. In other regions of Iran, 4% to 8% of people carry the gene (4). According to published reports, Sistan and Baluchestan province accounts for 2600 thalassemia major cases (5) with Zabol with 197 thalassemia cases (6).

Considering the prevalence of thalassemia major cases in Iran, studies show that despite considerable advances in medical and therapy sciences, by which the life of thalassemia cases has been prolonged from below 10 years to at most two or three decades, no significant attempt has been made to mitigate the various effects of this disease as well as its hard and permanent treatments (7). Similar to other chronic diseases, thalassemia, as a chronic disease, imposes serious physical, socio-mental, congenital and economic effects to the patients and their families (8). Physical problems such as chronic anemia, bone deformation, growth change, short height and delayed physical maturing on the one hand and unpleasant as well as long and repetitive therapies on the other hand affect different life aspects of the patients (9, 10). Disease duration and treatment period, increased hospitalization and therapy costs, mental status and social harms are among complexities affecting thalassemia patients and their families (11). Without the contribution of the patients, their treatment will not be enough effective and no satisfactory result will be obtained (12). Generally, the existence of a patient in a family provides the ground for the behavioral change of the family members and can naturally increase the family requirements. In Iran, thalassemia patients are among young population. Therefore, family plays a more important role in caring such patients (13). Self-efficacy, which is defined as the trust of an individual on his/her ability in doing self-care behaviors in special conditions, is an effective factor in promoting patients' quality of life (14). As an influential factor of the quality of life, self-efficacy emphasizes individuals' perception of their abilities in successfully performing a competent performance (15). Researches show that those individuals who trust their abilities actively participate in health programs promoting health level (16). Increased drug consumption, better relations with therapy team and promotion of health variables are among the positive outcomes of self-efficacy programs (17). In chronic diseases, training is a special part of care program by which patients actively participate in their health care programs and this, in turn, results in better interaction with clients. Training is an important aspect of nursing. According to Bandura's theory of self-efficiency, self-care training can further adopt patients with thalassemia and can make them accept and engage in self-care activities. This, in turn, reduces thalassemia side effects, increases self-sufficiency and can decrease patients' physical problems and promote the quality of life (18, 19).

Home-care means providing health cares and supports at home. Providing health care services to patients with chronic diseases, who require timely services, is an important reason underpins the advancement of homecare programs. Home-care objectives address decreased social care costs, improved quality of nursing activities, decreased convalescence duration and rehabilitation (20). Medical advances have increased training and support requirements of thalassemia patients. Therefore, home-care training and services reduces associated problems and inabilities and patients can predict their needs for training about their physical needs and therapy programs. To this end, researches decided to conduct this study in order to assess the effect of home-care training on the self-efficacy of thalassemia patients.

## 2. METHODS AND MATERIALS

## Participants

This quasi-experimental, case-control, before and after intervention study was conducted on 136 thalassemia major patients in Zabol, Iran from January 2014 to October 2015. The population of study was distributed in case and control groups with 68 members in each group. Sampling was conducted by simple random sampling method. The inclusion criteria were thalassemia patients who were interested in participating in this study and their acceptable cooperation in filling related forms. Exclusion criteria were incomplete filled self-efficacy questionnaire and no consent in participating in home-care training sessions.

#### Study Tool

Required data was collected using Sherer General Self-Efficacy questionnaire (SGSES) as well as forms for investigating demographic and clinical variables and care deficiencies (21). SGSES questionnaire was constituted of 17 items measuring three aspects of behavior including tendency to start, tendency to extend effort for completing a task and resistance against encountering barriers. Items were scored from 1 to 5 (1=completely disagree and 5= completely agree). This questionnaire is generally composed of 17 items where the score of items 3, 8, 9, 13 and 15 is increased from left to right and that of remained items is increased from right to left. The sum of scores of all 17 items is considered as the total score of each case. The higher score the higher selfefficacy. Wooduff and Cashman (1993) investigated SGSES scale and confirmed its validity and reliability (22). In Iran, Asgharnezhad et al confirmed its validity and reliability with a Cronbach's alpha of 0.83% (23).

## **Study Procedure**

Following necessary coordination with the center of special diseases, thalassemia department, in Zabol, 136 thalassemia cases were sampled using simple random sampling method and placed in case and control groups. Then, they were introduced with and informed of the study method. Both groups filled clinical demographic and SGSES questionnaires in order to obtain their consent for participating in this study. The case group, then, was subjected to the intervention, or training courses. Considering the training needs of cases, home-care training program was designed in the form of 30-45 minutes individual and group training sessions. The trainings were continued for one month for both groups as well as their caring persons. During the sessions, researchers vulgarized trainings considering the literacy level of patients and hinted no medical term. At the end of the 4<sup>th</sup> training session, which was the last session, the cases were provided with training instruction. It was a regular and comprehensive collection of all items and homecare tips explained in previous sessions. After two months, the self-efficacy of the cases of both case and control groups was assessed again. Their self-efficacy before and after intervention (home-care training) was compared in order to reveal the effects of home-care training on their self-efficacy.

### Statistical analysis

SPSS 21 was used to analyze data. In addition, mean, standard deviation and frequency distribution were used to describe demographic data. Chi-square, t-paired, ANOVA and t-independent were used to assess the relationship between demographic variables and efficacy. Sig. level was considered <0.05.

#### **3. RESULTS**

The age frequency of study units in case and control groups showed that the mean age of cases with thalassemia major was 16.98±5.37 in case group (the minimum and maximum ages were 2 and 30, respectively) while in control group it was 13.82±3.55 (the minimum and maximum ages were 9 and 25, respectively). Among the cases of both groups, 39 cases (57.4%) were female and 29 cases (42.6%) were male with female thalassemia major cases as the most frequent studied unit. In the case group, the education level of cases was as follows: 13 cases (19.1%) illiterate, 17 cases (25%) primary school, 14 cases (20%) guidance school, 22 cases (32.4%) high school and 2 cases (2.9%) university student. In the control group, the education level of cases were as follows: 23 cases (33.8%) illiterate, 30 cases (44.1%) primary

Mean care defi- ciency	Case group			Control group		
	Before interven- tion	After intervention	Willcoxon test	Beforeintervention	After intervention	Willcoxon test
Nutrition	1.07±0.99	0.16±0.37	P=0.000 Z=-5.81	1.77±1.21	1.69±1.08	P=0.447 Z=-0.712
Activity and rest	1.69±1.63	0.26±0.56	P=0.000 Z=-5.93	1.98±1.27	1.80±1.40	P=0.003 Z=-3.00
Drug consumption	0.42±0.71	0.0±0.0	P=0.000 Z=-4.17	1.11±0.92	1.05±0.97	P=0.206 Z=-1.25
Mental health	3.82±2.76	0.55±0.96	P=0.000 Z=-6.69	3.88±2.01	3.51±1.89	P=0.000 Z=-3.74

Table 3: comparison of care deficiencies of majeure thalassemia cases between case and control groups

school, 10 cases (14.7%) guidance school, 5 cases (14.7%) high school. Regarding marital status, 98.5% of cases were single in both groups. The diagnosis age was 6 months in 61.8% and 18.5% of cases of case and control groups, respectively with a mean diagnosis age of 16.98±5.37 and 13.82±3.55 in case and control groups, respectively. In both groups, blood transfusion interval of the majority of cases was 20 days.

The vast majority of thalassemia major cases (35 cases, 51.5%, in case group and 51 cases, 75%, in control group) were consuming OSVERAI as iron chelating medicine. However, 33 cases (48.5%) and 17 cases (25%) were consuming DESFERAL as iron chelating medicine in case and control groups, respectively. Regarding hemoglobin, the hemoglobin value was 9 and 9.5 in the majority of in case (47.1%) and control (42.6%) groups, respectively.

Case and control groups were compared in terms of the similarity of the following variables: sex (t-independent, P=0.787), education level (ANOVA, P=0.529), marital status (Chi square, P=0.575), diagnosis age (ANOVA, P=0.283), blood transfusion (Chi square, P=0.447) and iron chelating medicine (Chi square, P=0.177). The tests showed similar distribution of cases in case and control groups in terms of the above variables. In other words, the groups were homogeneous in terms of these specifications. However, the comparison revealed non-similar distribution in terms of hemoglobin (ANOVA, P=0.000).

In case group, the mean self-efficacy score was  $44.58\pm5.23$  before intervention. It increased to  $49.50\pm6.66$  after intervention which was significant according to t-paired test (P=0.000). In control group, the mean self-efficacy score was  $48.69\pm6.82$  before intervention which increased to  $49.69\pm6.81$  after intervention (t-paired, P=1.00) (Table 1).

t-paired test	After inter- vention	Before inter- vention	frequency	Mean self- efficacy group
P=0.000 t=7.86 df=67	49.50±5.23	44.58±5.23	68	Case group
P=1.00 t=0.000 df=67	49.69±6.81	48.69±6.82	68	Control group

Table 1. Comparison of self-efficacy score in case and control groups before and after intervention

Mean difference of self-efficacy was  $4.91\pm5.15$  and  $1\pm0.45$  in case and control groups, respectively which was not significant according to t-independent test (P=0.353) (Table 2)

t- indepen- dent	Control group	Case group	group
P=0.353 df=67 t=0.936	1±0.45	4.91±5.15	Mean difference of self- efficacy before and after intervention

Table 2. Comparison of mean difference of self-efficacy between case and control groups

In case group, mean care deficiencies was decreased after intervention. This decrease was significant in nutrition, activity and rest, drug consumption and mental health areas (Willocoxon test, P=0.000). The same descending trend was seen in control group but the decrease was significant only in activity and rest (P=0.003) and mental health (P=0.000) areas (Table 3).

Self-efficacy score difference was compared with diagnosis age, transfusion interval, hemoglobin, marital status, iron-chelating medicine and education level. According to statistical tests, the difference was not significant in both case and control groups. However, iron-chelating medicine was significant in the case group (Chi square, P=0.052).

## 4. DISCUSSION

This study was performed from 2014 to 2015 to assess the effect of home-care training on the self-efficacy of thalassemia patients. In this study, the self-efficacy of thalassemia major cases was 44.58±5.23 before intervention which was a low value. This finding agrees with the results of Esmaeili et al (2005) and Madanloo et al (2013) (24, 25). Medanloo et al (2013) found in their study that continuous trainings promote self-efficacy (25). It can be argued, therefore, that training is a proper tool for promoting the awareness of clients on the one hand and self-efficacy is not achieved without having sufficient knowledge and awareness of self-caring on the other hand (26). Training is an important aspect of nursing activity.

According to Bandura's theory of self-efficiency, providing thalassemia patients with self-care trainings can further adopt them with thalassemia and can make them accept and engage in self-care activities. This, in turn, decreases relevant side effects and creates self-sufficiency feeling in them which can decrease their physical problems on the one hand and promote the quality of life on the other hand (27).

This study was conducted on Zabol thalassemia patients in order to assess the effect of home-care training on their self-efficacy. According to results, mean self-efficacy score in control group was 48.69±6.82 before intervention which increased to 49.69±6.81 after intervention. In addition, mean self-efficacy score in case group was 44.58±5.23 before intervention which increased to 49.50±6.66 after intervention. The mean self-efficacy score of case group (after intervention) was significantly higher than that of control group ( $P \le 0.001$ ).

According to results, the self-efficacy of case group increased thanks to home-care trainings. This implies that training of thalassemia patients, and their family members, affects their self-efficacy. Unseal and Kapykcy trained arthritis patients for three weeks in their study. Their results showed the increase of the self-efficacy of case group compared with control group. This agrees with our study (28). Farrell et al trained 48 arthritis cases for six weeks. According to their results, this increased the self-efficacy of case group compared with control group (29).

Ahmadi et al believe that continuous cares with three months follow-up affect different indices including hospitalization interval, physical activity trend, physician visits and the quality of life of patients with coronary artery diseases (30). Nazil et al study showed that training of diabetes II patients affects performing regular exercises. They trained 42 patients of case group and assessed the effect of self-efficacy training after two weeks. Their results indicated the significant increase of mean scores in case group compared with control group. It can be argued, therefore, that behavior change is a pre-condition for the promotion of self-efficacy (31). In 2014, Akbari et al conducted a study to assess the effect of continuous care model on the selfefficacy of myocardial infraction patients in controlling the disease side effects. They concluded that continuous care model-based training can change the self-efficacy of such patients in controlling relevant side effects (32) which agrees with this study.

Laverty et al conducted a two-week training program with six weeks follow-up on bronchiectasis patients and showed the increase of the self-efficacy of the cases (33) which agrees with this study. In addition, Savadkouh et al (34) and SONG (35) conducted training and follow-up programs and could promote the self-efficacy of their patients. This agrees with our results. Mohammadinezhad et al conducted a study in 2015 and concluded a significant difference in the self-efficacy index between case and control groups after 8 weeks of training (36).

Our results for promoting the self-efficacy of thalassemia major cases agree with the results of Ahmadi et al in 2014. They studied the effect of self-care programs on the selfefficacy of anemia sickle cell patients and concluded that self-care programs has a positive effect on their self-efficacy so that the self-efficacy, which was at a moderate level prior to intervention, increased after intervention (37). Moreover, Cashaw conducted a quasi-experimental study on a group to assess the effect of self-managing based on behavioral intervention. They concluded that the self-efficacy of participants was at a moderate level prior to intervention but it increased after intervention (38).

## **5. CONCLUSION**

According to our results, home-care training can promote the self-efficacy of thalassemia major patients. In home-care trainings, patients play an active role in caring themselves. By providing home-care trainings, therefore, essential steps should be taken to promote their self-efficacy and to mitigate relevant problems. Concentrating on the results of this study and its effect on the self-efficacy of thalassemia cases, it is recommended to further adopt home-care trainings in order to achieve self-caring and to improve self-efficacy.

• Conflict of interest: none declared.

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