

The Effect of Orem Self-care Model on Health-related Quality of Life of Patients with Thalassemia Major

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ABSTRACT

Introduction and Objective: Thalassemia and its complications affect the quality of life of these individuals. Therefore, nursing interventions by nurses as essential careers of these patients are necessary. The aim of this study was to determine the effect of Orem's self-care model on the quality of life associated with the disease in patients with β -thalassemia major.

Methods: This is a semi-experimental interventional study with pre-test and post-test design. This study was performed on 80 patients with β -thalassemia in Dezful-Iran in 2015 and then randomly divided into two groups of 40 subjects. Data collection tool was SF-36 questionnaire. Educational package, self-care based on need assessment and based on Orem self-care model, was taught to patients in a 60 minute session.

Results: There was no significant difference between the two groups in terms of demographic variables ($p>0.005$). The results showed that there was a significant difference between the pre-test and post-test scores of the control and education groups in terms of quality of life were observed ($p<0.005$).

Conclusion: Orem self-care can increase the quality of life of patients with major β -thalassemia. Therefore, this method can be used as a simple and low cost supplementary non-pharmacological treatment in order to increase the quality of life associated with their health.

Key words: Self-care, Orem self-care model, Health-related quality of life, Beta-thalassemia major

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INTRODUCTION

More than 200 different genetic defects have been diagnosed [1]. Thalassemia is the most common form of hereditary anaemia [2]. In the past several years, despite the decline in the world, especially among the Mediterranean population, where the prevalence and carrying capacity are remarkably high, thalassemia still remains an important public health issue [3]. The characteristic of β -thalassemia disorder is the production of defective haemoglobin and excessive destruction of red blood cells [4]. The main treatment in these patients is

blood transfusion, which causes the normal growth and development of the cells and ineffective hematopoietic suppression [1]. The more severe form of β thalassemia major, requiring regular blood transfusion at an early age, can lead to premature death if not treated [5]. Thalassemia influences physical appearance, such as apparent deformity, delayed growth, and late maturity on physical health, may have an effect on the physical appearance, such as bone anomalies and short stature, all affecting the image of the weak.

Other complications such as heart failure, cardiac arrhythmia, liver disease, endocrine disorder and infection in β -thalassemia patients are common and may have a negative impact on the quality of life of patients [6]. In addition, as with all chronic diseases, patients with β thalassemia major are also at risk of emotional and

behavioral problems [7]. According to Kaheni et al., 44% of thalassemia patients had psychological problems, 74% had poor quality of life, 67% had symptoms of anxiety, 62% had emotional problems, especially depression, and 49% had communication problems [8]. Nevertheless, the number of studies that have addressed such problems in their care is limited [7]. With modern medical treatments, the mortality rate for thalassemia has declined significantly, and now that there is a remarkable ability to treat each patient and allocate health care resources, quality of life should be considered as an important indicator of health care and safety issues [6]. The concept of quality of life is defined as "understanding individuals from their position in life within the framework of the cultural and value systems in which they live and in relation to their goals, expectations, standards and priorities" [9].

Self-management education has long been considered as the cornerstone of care for chronic diseases [10]. Self-care is defined as "self-regulated activities" or "living environment" for the purpose of setting up a program for the preservation of life, integrated function, and well-being [11]. Therefore, it is imperative that patients are involved in self-care and are encouraged to take on some of their care responsibilities to help control chronic illness and the cost of healthcare associated with it [12]. Self-care behaviors, however, require education about illness and its management, and psychological empowerment of patients for full participation in their care [13]. Self-care was taken for the first time in nursing in 1958, when Orem began to think of the need of individuals for nursing care and how they could help them [14]. Orem referred to self-care as a regulative function of humanity. The self-care model focuses on the individual's ability to take care of life, health, and well-being. The basic principle in Orem's model is that people can be responsible for their own health and for others. And like other self-care activities, its goal is to meet the needs of self-care [15].

Available studies indicate that the self-care model has been used in various fields. These studies have been conducted in different groups such as dialysis patients, hospitalized patients, cancer patients, diabetes, multiple sclerosis and home-based care patients. The results of these studies showed that the self-care model of Orem was helpful and increased its self-care [16]; therefore, this study was conducted to determine the effect of Orem self-care model on quality of life associated with the health of patients with thalassemia major in Dezful.

MATERIALS AND METHODS

This is a semi-experimental interventional study in which sampling was done after explaining the purpose of the study; obtaining permission from relevant authorities and obtaining informed written consent from patients with thalassemia major referring to the department of thalassemia in Dezful Hospital or their supervisor in Dezful-Iran in 2015 with available method. This article is based on a research project approved by Dezful

University of Medical Sciences with the code DURS-121 and has a clinical trial code IRCT2014121219733N2.

Criteria for entry into the study were major thalassemia; referral for regular blood transfusion; the patient did not receive planned self-care information; aged 15 years to 25 years; had at least one hospital stay and no history of illness, acute or chronic diseases such as hepatitis, heart and kidney failure, cancer, asthma and chronic obstructive airway disease. Patients who participated in a training program at the same time or were not willing to continue to participate in the study were excluded.

The data gathering method was interviewing and filling out a questionnaire. The instrument of the study was demographic information and quality of life questionnaire. The demographic questionnaire included age, sex, BMI, ethnicity, educational level, occupation, marital status, monthly income, hospitalization and drug use.

A 36-question SF-36 questionnaire was used to investigate the patients' quality of life. The questions include 8 concepts: physical function, social function, role disorder due to physical health, pain, general health, and role disorder due to emotional health, energy/fatigue, and emotional well-being domains. Each question had a maximum score of 100 and a minimum of zero. The average of total scores of all 8 concepts will be calculated to measure the total score of quality of life. The average of each concept will be calculated for each individual. A score less than 50 mean low quality of the concept and more than 50 means high quality.

SF-36 Questionnaire of quality of life is a standard criterion which is considered to be used in research and clinical practice, hygiene policy evaluation, health, and health status checking of general population. Using Cronbach's alpha test, in 1992 in the UK, Brazier et al. determined its reliability above 85% [17]. In Iran Montazeri et al. in a study with the aim of translation, reliability and validity determination of Persian version of SF-36 questionnaire showed that except for the vitality scale ($\alpha=0.65$), other scales of Persian version of SF-36 enjoy the minimum standard of reliability coefficients in the range of 0.77 to 0.9 [18].

After the initial selection of samples (according to admission conditions), the researchers provided a census and explanation of the nature and manner of implementing the program for patients, provided them with two questionnaires of demographic information and quality of life SF-36. After completing and collecting questionnaires, 80 patients with thalassemia who had the required conditions for participation in the study were randomly divided into two groups (case and control) in the experimental and control groups (each group was 40). Patients in the test group were divided into separate groups of five. Then, a self-care curriculum based on the Orem model based on the needs assessment, in the form of a lecture session, a question and answer, a presentation of PowerPoint, a photo presentation, and an educational pamphlet by a researcher at the doctor's office in Ganjavian Hospital for

each of them; the test groups were held. Orem self-care educational curriculum based on self-care ability and their educational needs (using a validated needle-based checklist). This session lasted 60 minutes, which was subdivided into three 20 minute intervals to prevent fatigue in patients. During the meeting, the content was presented in plain language, comprehensible and without the use of technical and medical terms. In the last 20 minutes, the questions were answered, and if they were not understood for the illness, they were told separately, discussed and understood. The scheduling of the session was determined by the patients' opinion and their occupation.

At the end of the session they provided the educational pamphlets for patients and also the possibility of private counselling was given to the patients. The researcher contacted the patients in the test group every week, answering their questions and problems during the course of the program, and supporting the clients to better implement the program (educational support system based on Orem's self-care model). After 3 months of follow up, the quality of life questionnaire (SF-36) was again measured by patients in the experimental and control group, completed, and quality of life after the implementation of the self-care program. At the end, in order to observe the ethical issues of the subjects taught to the test group, the control group was also trained and the educational pamphlets were provided to them. The educational pamphlets of these patients were prepared by the researchers based on valid references and confirmed by 10 faculty members of Dezful University of Medical Sciences for scientific confirmation and validity.

To compare demographic and baseline characteristics of groups, independent samples t-test was used for continuous variables, and Pearson chi-square tests were conducted for nominal variables. Generalized Estimating Equation (GEE) models were applied to examine the associations between group (intervention/control) and change in health-related quality of life indices over time. GEE models included two main effects (group and time) and the interaction of these effects. Time points in the analyses included baseline and visits immediately after intervention and weeks 12. All tests applied were two-sided and a significance level of 0.05 was considered significant. All statistical analysis were performed with statistical software SPSS 16.0.0. (SPSS Inc. Chicago, IL, USA).

RESULTS

Eighty eligible patients with major thalassemia were entered the study who were randomly allocated into two groups. The baseline demographic characteristics of the participants are summarized in Table 1. Forty patients in intervention group and 40 patients in control group attended the pre-determined visits (visits after and 12) after the baseline visit. The two groups did not differ significantly in gender, age, ethnicity, marriage status, education level, living place, blood group, hospitalization history and surgery history of the study participants (Table 1).

Table 1: Baseline characteristics of the participants

Characteristics	Control Group (n=40)	Intervention Group (n=40)	p-value
Age (year)			0.06
Mean ± SD (range)	24.12 ± 4.96 (14-32)	24.35 ± 5.50 (14-39)	
Gender			0.82
Female	16 (41.0%)	15 (62.5%)	
Male	23 (59.0%)	25 (37.5%)	
Ethnicity			-
Fars	10 (25.0%)	18 (45.0%)	
Other	30 (75.0%)	22 (55.0%)	
Marriage			0.75
Single	33 (82.5%)	35 (87.5%)	
Married	7 (17.5%)	5 (12.5%)	
Education			-
Less than 12 years	21 (52.5%)	15 (62.5%)	
More than 14 years	19 (47.5%)	25 (27.5%)	
Living Place			0.16
Urban	22 (55.0%)	29 (72.5%)	
Rural	18 (45.0%)	11 (27.5%)	

Blood Group			--
A	13 (32.5%)	14 (35.0%)	
B	5 (12.5%)	11 (27.5%)	
O	18 (45.0%)	14 (35.0%)	
AB	4 (10.0%)	1 (2.5%)	
Hospitalization History			0.49
Yes	21 (52.5%)	25 (62.5%)	
No	19 (47.5%)	15 (37.5%)	
Surgery History			0.64
Yes	13 (32.5%)	16 (40.0%)	
No	27 (67.5%)	24 (60.0%)	

Data are expressed as No. (%) unless otherwise stated

The quality of life score of the study groups at baseline and follow-up visits are presented in Table 2. The mean score of role disorder due to emotional health, tiredness score, emotional welfare score, pain score and mental health score reduced significantly over time of study in control group while they were significantly increased in intervention group (Table 2). The mean score of role disorder due to physical health, social function, physical

health and quality of life reduced significantly over time control group. These items reduced significantly till after and remained unchanged till the end of study (Table 2). The mean physical health score decreased significantly over time in control group. In the intervention group, a significant increase was observed till after and at the end of study compared to baseline in the mean scores (Table 2).

Table 2: Score of SF-36 questionnaire over time between the two study groups

Questionnaire	Time of Study			p-value
	Baseline	After	Week 12	
Physical				0.003
Control Group	80.12 (3.27)	80.25 (3.23)	79.87 (2.70)	
Intervention Group	84.12 (2.83)	86.37 (2.34)	85.75 (2.18)	
Role Disorder Due to Physical Health				0.002
Control Group	67.50 (4.58)	66.00 (4.48)	61.87 (4.10)	
Intervention Group	74.37 (5.76)	82.50 (3.81)	75.12 (4.27)	
Role Disorder Due to Emotional Health				0.001
Control Group	67.47 (5.26)	64.96 (5.19)	64.13 (5.11)	
Intervention Group	72.48 (5.71)	77.48 (4.97)	79.97 (3.92)	
Tiredness				<0.0001
Control Group	61.12 (3.25)	60.75 (3.24)	58.75 (3.22)	
Intervention Group	70.62 (3.75)	74.87 (3.28)	75.50 (2.88)	
Emotional Welfare				<0.001
Control Group	66.65 (2.94)	65.95 (2.94)	65.85 (2.74)	
Intervention Group	75.20 (3.34)	77.60 (2.90)	77.90 (2.84)	
Social Function				<0.0001
Control Group	68.12 (3.76)	65.31 (3.81)	64.06 (3.44)	
Intervention Group	79.00 (3.29)	83.75 (2.76)	83.12 (2.77)	
Pain				<0.0001

Control Group	79.12 (3.47)	77.18 (3.47)	74.06 (3.24)
Intervention Group	84.37 (3.08)	88.00 (2.52)	87.56 (2.41)
General Health			<0.0001
Control Group	60.68 (2.58)	56.93 (2.44)	57.68 (2.48)
Intervention Group	66.37 (3.69)	71.87 (3.07)	69.75 (3.21)
Physical Health			<0.0001
Control Group	71.70 (2.35)	70.09 (2.24)	68.37 (2.03)
Intervention Group	77.33 (2.85)	82.18 (2.10)	79.53 (2.15)
Mental Health			<0.0001
Control Group	67.44 (2.93)	64.24 (3.03)	63.19 (2.85)
Intervention Group	74.32 (3.23)	78.42 (2.71)	79.08 (2.34)
Quality of Life			<0.001
Control Group	68.02 (2.51)	67.16 (2.40)	65.78 (2.21)
Intervention Group	75.40 (2.89)	80.07 (2.17)	79.30 (1.94)
*The p-value for Group; *Time interaction (Based on the results of GEE analysis)			
The values are expressed as mean (SE)			

DISCUSSION

Chronic diseases today are the greatest challenge to the health of the community and are responsible for over 80% of deaths [19]. One of these diseases is major thalassemia, which has no permanent treatment. Major thalassemia is one of the most commonly diagnosed genetic hemoglobinopathies associated with severe anaemia, and these individuals have a need for blood transfusion to survive [20-23]. Because of various and complex drug treatments, these people have a variety of problems and rooted changes in the way of life that affect their social and psychological functioning and, with age, their quality of life is significantly reduced. The research was conducted with the general purpose of "The effect of Orem's self-care model on quality of life in patients with thalassemia major". In this regard, the findings show the positive effect of Orem's self-care pattern on the quality of life of these patients.

According to the results obtained in this study, demographic factors that seemed to affect the ability of patients with thalassemia major to have a significant effect were not statistically significant and the two groups were similar. Demographic data consistent with in the study of Zarandi *et al.* [24] regarding the effect of the Orem self-care model on the quality of life of patients with migraine and the study of Safizadeh *et al.* [25] regarding the effect of Orem's self-care pattern on patients with myocardial infarction and also the study of Mohammad *et al.* [26] regarding the ability of self-care based on the Orem pattern on patients with coronary artery disease.

In this study, based on the results, the mean scores of physical health and its dimensions after the Orem self-care pattern in the intervention group showed a significant increase compared to the control group

compared to the pre-study. Patients with thalassemia have a lot of physical complications because the ability to carry oxygen to tissues is reduced and tissue hypoxia leads to cardiovascular and pulmonary dysfunction, which results in heart failure, arrhythmias, and some degree of airway obstruction. Also, due to the increased concentration of ferritin in the blood, these patients experience problems with the peripheral nervous system and the musculoskeletal system, as well as ocular, ears, pharyngeal and joint complications. All of these complications are the reason for their quality of life to decrease in the physical aspect. The present study uses a self-care model to have a significant effect on it. The present study confirms the results of many other studies that have been carried out on the Orem self-care model.

For example, a study by Hashemi *et al.* [27] on the quality of life of burned patients using the Orem self-care model indicated that there was a significant difference in terms of quality of life in the control and control groups and also in the control group, the increase in quality of life in one and two months after the intervention showed a growing trend in terms of quality of life, while quality of life in the control group after the intervention showed a decreasing trend compared to the pre-intervention period which is consistent with the present study and may be due to poor quality of life due to drug complications, deformity, dysfunction, etc. Also, in a semi-experimental study on teens with haemophilia in Tehran showed Effect of Care Showed that the quality of life scores in the experimental group was significantly different from that of the control group [27].

Also, in the present study, the mean mental health scores of people with thalassemia major in the post-test group were significantly different in the intervention group compared to the control group, while the two groups did not have any significant difference in this regard before

the study. The issue of the effectiveness of self-care method is to improve the quality of life of patients. Mikelli *et al.* [28] showed that adolescents with major thalassemia had a higher depression and lower quality of life than healthy ones. This study was consistent with the present study. Both groups had lower mental health and in the control group, after using self-care model, the mean scores in the post-test group were significantly different in comparison with the control group. In confirmation, patients with thalassemia, in addition to high costs, often suffer from body impairment, loss of physical functioning of the body following anxiety and depression and lack of family support, all of which have a negative effect on their quality of life in particular, in this study, the mean score of mental health components was low in both groups. Using OREM self-care pattern caused a change in control group compared to control group.

Overall, the results of this study showed that quality of life has increased significantly after the use of Orem's self-care pattern in the test group compared to the control group, which means that thalassemia patients are at risk of non-management self-management. As a result, self-care and counselling is very important in these patients. Orem also pointed out that patients who have low levels of self-care knowledge are motivated and lack of self-care experience, which therefore require training and counselling [25]. Therefore, interventions such as educational interventions, support and empowerment for these patients should be addressed to help them cope with problems. The results of this study are consistent with other studies that have influenced the effectiveness of self-care programs in promoting the quality of life of chronic patients including the studies by Hashemi *et al.* [27], the effect of the Orem self-care program on the quality of life of burned patients referring to Shiraz Hospital showed that their quality of life increased after using the Orem self-care model. Also, in a study by Hemati *et al.* with the aim of influencing Orem's self-care pattern on adolescent asthma stress, education based on the Orem model has had a positive effect on reducing perceived stress by adolescents with asthma [29]. Whereas the study, however, is in contradiction with the study by Mahmoudi *et al.* [30] entitled "The Impact of Self-Care Program on Quality of Life in Patients with Sick cell anaemia". They stated that the overall quality of life score in the test group was not significantly different before and after intervention, which may be due to the type of disease, the age of the patients, and the duration of the disease. Also, in a study by Davodi *et al.* [31] on patients with oesophageal cancer, the overall quality of life score after intervention was not significantly different between the two groups, which contrast with the present study. This difference may be due to the type of disease and the change in the number of training sessions. According to the results of this study, it can be said that the design and implementation of an educational program based on the Orem self-care model, considering the mental and physical problems of patients with thalassemia, can, in addition to improving their quality of life, reduce the cost of health care, reduce mental problems and achievement of optimum health.

CONCLUSION

Since the Orem self-care model has led to positive outcomes in reducing disability, saving on treatment costs and increasing quality of life, it is suggested that Orem Self-Care Theory be added to the curriculum of undergraduate nursing students and the planning of continuing education and by educating nurses and students with clinical skills, we can reduce the incidence of thalassemia patients. Patients with β -thalassemia require much self-care, support, and counselling, and hence nurses and other health care providers are actively involved in improving self-care ability in these patients.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest regarding the publication of this article.

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