

The effectiveness of resilience training and stress management (SMART) on the quality of life in patients with thalassemia major

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Abstract

Background: Thalassemia is one of the most common genetic diseases in Iran with different physical and psychosocial consequences which affect these patients quality of life .

Objectives: The purpose of this study was to investigate the effect of resilience training and stress management on the quality of life in patients with thalassemia major in Kerman-Iran.

Methods: In this quasi-experimental study with pre-test and post-test design and a control group, 30 patients referred to Samen-al-Hojaj (AS) charity group, were selected by convenience sampling method and randomly divided into two experimental and control groups (each of 15 patients). After completing the pre-test, the experimental group received 10 sessions of training and stress management. Control group received no intervention. The data collection tool was the questionnaire of quality of life (SF-36). Data were analyzed by SPSS software using the covariance analysis.

Results: The results of the covariance analysis in the studied variables indicate that the effect of the group (experimental intervention) on the post-test of physical function, general health, the role limitation for physical and emotional health were significant and respectively were (P=0.005 and F=11.22), (P=0.001 and F=16/02) and (P=0.049, F=4.3). However, the effect of the group on the post-test of role limitation for emotional reasons, physical pain, social function, and fatigue or vitality were not significant and respectively were (P=0.20 and F=1.741), (P=0.774 and F=0.085), (P=0.674 and F=0.183) and (P=0.288 and F=1.203).

Conclusion: According to the results, based on the effectiveness of stress relief and management on some components of the quality of life in patients with thalassemia major, this study can be used to reach an effective solution to improve the quality of life and generally improve the mental status of patients.

Key words: *resiliency training, stress management, quality of life, thalassemia major*

Introduction

Thalassemia is a congenital autosomal recessive disorder and is a hereditary hemoglobinopathy due to a defect in the production of globin chains that requires special medical treatment. These patients need to inject regular blood and iron intoxication for survival [1]. Thalassemia is one of the most common genetic diseases in Iran and in the world [2]. There are about 333 million thalassemic patients worldwide, 99 million of whom live in southeastern Asia. Iran, with about

23333 thalassemic patients and 3 million thalassemic carriers, is one of the countries located on the thalassemia waistline in the world [4]. The hereditary nature of the disease, the manifestation of the disease in the early years of life, the appearance change, the expectation of early death and the need for continuous treatment, have a great impact on the patient's mental development and the mental relaxation of his family. These patients are subjected to various pressures such as feeling humiliated, frustrated,

anxious, worried about school and occupation, medical problems, social and educational issues [5-7]. Nowadays, with the help of existing therapies and the use of new drugs to improve iron overload control and starting a timely treatment, the disease has turned into a chronic disease and life expectancy in these patients has increased [1,8]. However, the repeated and prolonged use of drugs has an impact on other aspects of their lives, and significantly affects their mental health and quality of life [9]. Studies have shown that these patients have a lower quality of life than their peers [2,10-12]. On the other hand, when they reach the young age, in addition to physical problems and functional limitations, other problems such as family formation, higher education and finding a suitable job will affect family and the health care system in the country. These factors result in many psychological problems in these patients and negatively affect their quality of life [13,14]. WHO defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment [15].

The study by Mohammadi et al. Revealed that 62.5% of the studied patients with beta thalassemia had mental disorders and 72.5% of the patients reported the moderate quality of life [14]. Other studies also showed that patients with major thalassemia had more depression and mental disorders and poorer quality of life than healthy ones [3,16,17].

Resilience refers to the dynamic process of positive matching with bitter and unpleasant experiences. Improving the level of resilience and increasing the level of tolerance of a person in coping with stressful situations can modify the helplessness of a person under stressful conditions and increases the individual's spirit, physical and mental health [18]. Research findings suggest that the resiliency training reduces the stress and improves the resilience, and uses coping strategies

and more favorable defense mechanisms in people with stress and stressful illness [19].

The cognitive-behavioral stress management intends to increase the sense of control, self-efficacy, self-esteem, effective coping and social support. This will reduce the negative mood and social isolation changes and improve the quality of life [20]. Therefore, the study of the effect of psychological treatments on reducing the symptoms of disorders in thalassemic patients is considered essential. Therefore, in this research, the effectiveness of resilience training and stress management (SMART) on the quality of Life in the major thalassemia Patients has been studied.

Methods

This study was a quasi-experimental study with with pre-test post-test design and a control group. This study ethics code was E.A.95.08.02. After approving the ethics committee of Shahid Bahonar University of Kerman-Iran, the research sampels were selected by convenience method and randomly allocated by coin tossing into two groups of experiment and control. It should be noted that all participants expressed their written consent to participate in the research. Data were collected by Warren and Sherborne Quality of life questionnaire (SF-36) [21]. The questionnaire has 36 questions that assess eight different areas of health. The physical function (10 items), the general health (5 items), the role limitation for physical reasons (4 items), the role limitation for emotional reasons (3 items), the physical pain (2 items), the social function (2 items) Fatigue or validity (4 items) and the emotional health (5 items) which assesses the individual's quality of life. The lowest score in this questionnaire is zero and the highest is 100. The score of each dimension is determined by rating the points in that dimension. The validity and reliability of the Persian version of this questionnaire in Iran have been confirmed in thalassemia major patients ($\alpha=0.915$). Montazeri et al. have declared this questionnaire through Cronbach's alpha of 0.77-0.9% [22]. The overall reliability coefficient of quality of life questionnaire (SF-36) in this study was 0.79.

The population of this study included thalassemia major patients referring to Samen-ol-Hojaj charity

institute in Kerman city in 2015. Individuals who have been diagnosed with the thalassemia major by a specialist, referred to the researcher and after completing a basic form that includes questions about personal details such as age, gender, marital status, education, if they were desired and had the following criteria they would be selected: Entry criteria: 1- Physically able to attend meetings. 2- Being in the age range of 20 to 30 years old. 3- At least having a diploma degree. 4- being the residents of Kerman city. Exit criteria: 1- History of participation in resilient training and stress management workshops. 2- Using the psychiatric drugs. Thus, after listing 271 thalassemia major patients who referred to Samen-ol-Hajj charity, 30 of them were selected and randomly allocated to experimental and control group.

The experimental researches are defined for at least 15 individuals per group [23]. It should be noted that the absence of more than two sessions also led to the departure of a person from the study and his removal from the course. In order to

perform the pre-test, the quality of life questionnaire (SF-36) was completed by the subjects of both groups. Then, the subjects in the experimental group received the treatment for ten weeks. Each session lasted 120-minute. After completing 10 sessions of group therapy, again, both groups were tested by means of the research tool. It should be noted that only experimental group was trained in a cognitive-behavioral stress management. To determine the intervention plan, the cognitive-behavioral model presented by Anthony et al. was used [20].

After assessing the patients and ensuring their conditions for participation in the research, the therapeutic sessions were conducted in collaboration with the therapist. In this intervention, the stress coping strategies were trained to the patients. Descriptions of the sessions are shown in Table 1.

The collected data was analyzed by ANCOVA covariance test using the SPSS software.

Table 1: The Content of training sessions

| Session | The content of the presented training sessions. |
|---------|--|
| First | the logic and necessity of resilience and stress management: Familiarity with stress and stress responses, gradual muscle relaxation for 16 muscle group |
| Second | Stress and Consciousness: Exercises for raising awareness about stressors, physical signs of stress, and the effects of stress and the concept of persistence, familiarity with the effects of individual assessment of the position with stress, gradual muscle relaxation for 8 muscle groups, respiration Diaphragm, mental imagery |
| Third | automatic thoughts and cognitive distortions: The association of thoughts and excitement, familiarity with automatic thoughts and self-reflection, familiarity with various kinds of cognitive distortions, identification of negative thoughts, cognitive reconstruction, gradual muscle relaxation for four muscle groups, diaphragmatic breathing, mental imagery |
| Fourth | the replacement of automatic thoughts: More familiarity with cognitive distortions and negative thoughts, familiarity with the types of selfishness, familiarity with the phases of rational thinking substitution, gradual passive muscle relaxation, a blend of diaphragmatic breathing and mental imagery. |
| Fifth | Coping (Section 1): Understanding the Concept of Coping, Understanding Coping types, Understanding Coping Styles with Position, self-Admission training for Heaviness and Heat. |
| Sixth | .coping (Section 2): Understanding the steps of matching coping styles with position, relaxation through recall, breathing a diaphragm. |
| Seventh | Managing anger: Spreading awareness of the anger and its various symptoms, different patterns of anger, identifying the cause of anger and strategies of anger management, mantra meditation |
| Eighth | Expression Training: Understanding interpersonal communication styles, types of expressive styles, familiarity with the barriers to expression, breathing count meditation |
| Ninth | Social Support: Familiarity with the Definition and Advantages of Social Support, Familiarity with Various Social Support Resources, Breathing counts Meditation |
| Tenth | Conclusion: Examining the progress of the subjects, reviewing the skills learned in the previous sessions and generalizing the lessons. |

Results

The results of the demographic characteristics section indicate that in the control group, 10 (33.3%) were between 20 to 25 years old and 5 (16.7%) were between 26 and 30 years old. In the experimental group, 8(26.7%) were between 20 and 25 years old and 7(23.3%) were between 26 and 30 years of age. Also, in the control group, 6 (20%) had a diploma, 7 (23.3%) had a bachelor's

degree, and 2(6.7%) had master's degrees. In the experimental group, 7(23.3%) had a diploma, 5(16.7%) were bachelor and 3(10%) had master's degrees. Regarding the data normalization and the homogeneity of variances in the pre-test and post-test, a covariance analysis test was used to analyze the data. The descriptive statistics of pre-test and post-test variables of quality of life and its subscales are presented in Table 2.

Table 2: Descriptive statistics of pre-test and post-test scores of quality of life components in experimental and control groups

| Components of quality of life | Group | Pre-test | | Post- test | |
|---------------------------------------|-------------------|----------|--------------------|------------|--------------------|
| | | Mean | Standard deviation | Mean | Standard deviation |
| Total score | Contol n=15 | 59 | 16.12 | 60 | 14.48 |
| | Expriment n=15 | 57.87 | 14.904 | 73.47 | 14.09 |
| Physical function | Contol n=15 | 60.67 | 25.76 | 60.67 | 22.02 |
| | Expriment n=15 | 61.67 | 20.84 | 79.67 | 19.95 |
| general health | Contol n=15 | 56.67 | 19.05 | 57.33 | 14.62 |
| | Expriment n=15 | 60 | 20 | 72.33 | 18.01 |
| Role limitation for physical reasons | Contol n=15 | 48.33 | 35.94 | 53.33 | 39.94 |
| | Expriment n=15 | 43.33 | 39.49 | 71.67 | 22.88 |
| Role limitation for emotional reasons | Contol n=15 | 53.31 | 41.45 | 60 | 40.29 |
| | Expriment n=15 | 48.8 | 37.57 | 68.93 | 32.11 |
| Physical pain | Contol n=15 | 57.17 | 15.46 | 63 | 16.66 |
| | Exprimen n=15t | 64.33 | 20.03 | 65.83 | 20.47 |
| Social function | Contol n=15 | 64.97 | 17.17 | 67.5 | 19.36 |
| | Exprimen n=15t | 63.6 | 12.89 | 79.17 | 9.047 |
| Fatigue or vitality | Contol n=15 | 61.33 | 13.29 | 63.67 | 13.02 |
| | Exprimen n=15t | 59.67 | 15.97 | 60.67 | 15.33 |
| Emotional health | Contol n=15 | 70.93 | 13.97 | 70.67 | 13.23 |
| | Expriment n=15 | 62.13 | 14.72 | 73.6 | 12.83 |

The results of the covariance analysis in the studied variables indicate that the effect of the

group (experimental intervention) on the post-test of physical function, general health, the role

limitation for physical and emotional health were significant and respectively were ($P=0.005$ and $F=11.22$), ($P=0.001$ and $F=16/02$) and ($P=0.049$, $F=4.3$). However, the effect of the group on the post-test of role limitation for emotional reasons, physical pain, social function, and fatigue or vitality were not significant and respectively were ($P=0.20$ and $F=1.741$), ($P=0.774$ and $F=0.085$), ($P=0.674$ and $F=0.183$) and ($P=0.288$ and

$F=1.203$). In general, according to the results, it can be concluded that the effect of intervention has increased the subscales of physical function, general health, role limitation for physical and emotional health in the experimental group, while increasing the role of limitation for emotional reasons, the physical pain, the social function and tiredness or joy.

Table 3: Covariance analysis of the effectiveness of stress management training on quality of life and dependent variables.

| Source of Changes | Subscale | Total squares | Degree of freedom | Mean | F | p | ETA Squared |
|-----------------------|--------------------------------------|---------------|-------------------|---------|-------|-------|-------------|
| | Physical function | 1444.11 | 1 | 1444.11 | 11.22 | 0.005 | 0.445 |
| | general health | 1698.99 | 1 | 1698.99 | 16.02 | 0.001 | 0.5 |
| | Role limitation for physical reason | 2848.95 | 1 | 2848.95 | 4.3 | 0.049 | 0.152 |
| Group or intervention | Role limitation for emotional reason | 1085.26 | 1 | 1085.26 | 1.741 | 0.20 | 0.07 |
| | Physical pain | 22.73 | 1 | 22.73 | 0.085 | 0.774 | 0.004 |
| | Social function | 9.191 | 1 | 9.191 | 0.183 | 0.674 | 0.01 |
| | Fatigue or vitality | 98.83 | 1 | 98.83 | 1.203 | 0.288 | 0.066 |
| | Emotional health | 458.45 | 1 | 458.45 | 5.235 | 0.037 | 0.259 |

Discussion

The purpose of this study was to determine the effectiveness of teaching resilience skills and stress management on the quality of life in patients with thalassemia major. The results of the research regarding the effectiveness of training on resilient skills and stress management were significant in increasing the quality of life. these findings are similar to that of Imani et al [2]. The results of this study showed that participation in group activities can increase the ability of the thalassemia patient to perform daily activities without being dependent on others and it has a positive impact on the quality of their life.

The result of the study of the effect of training on resilient skills and stress management on increasing the quality of life in patients with thalassemia major showed that despite being homogeneous before intervention, the difference between two groups in the overall score of quality of life after the resiliency and stress management training workshop was significant and in favor of the intervention group. The results of this study

were compared with the findings of Daadras et al. That says the effect of training stress management skills on blood glucose control, quality of life and stress in type 2 diabetic women is in the same direction [24]. On the other hand, the results of Jajermaneh et al showed that the stress management training program can be an appropriate approach to increase the self-efficacy of mothers with thalassemic children [25]. On the other hand, in the study of Asadi and Askari the implementation of cognitive behavioral group therapy could significantly increase the mental health in patients with thalassemia [26]. Also, Amir Rezaei Ordani and his colleagues referred to the effective role of the cognitive-behavioral stress management programs on stress, anxiety and quality of life in women with cancer [27]. The results of Kiani et al. research showed that the cognitive-behavioral group therapy can reduce the disappointment and increase the self esteem [28]. In explaining these findings, Toron's study suggests that the cognitive therapy for patients with chronic pain is one of the most effective

approaches. This treatment can reduce the anger, anxiety, fear and depression of these patients. The results of his study also showed that this approach is more efficient and more economical. Individuals in the treatment groups will learn a lot in the feedback received from each other [29]. Resiliency training, stress management and relaxation training with the neutralization of some effects of stressors and stress responses can help the individual's psychological and physiological functions. The techniques used to correct and change the way people look at stressful events, promote strategies for coping with stress and reduce the physical stress responses helps maintain a person's health.

Stress response processes can affect the psychosocial-immunological processes associated with disease progression. The intervention of stress management in a cognitive-behavioral way can be effective by increasing the sense of control, self-esteem, the adaptive coping and social support on the psycho-neuro-cognitive-psychological process. It seems that these changes reduce the negative mood and social status of the person and improves the individual's quality of life [20].

On the consequences of resilience, a number of studies have pointed to the increased mental health and life satisfaction. For example, Samaani, Jokaar and Sahraagard in their research showed that the resilience due to the reduced emotional problems (and with increased mental health) leads to satisfaction with life [30]. The study also had some limitations. Due to the limited research sample in Kerman-Iran and the evaluation of patients at some point in time should be with caution in generalizing the findings. Also, since this study only focused on patients with thalassemia major, the results can not be generalized to all chronic medical patients. Given the age limitations of sociological research in this study, researchers interested in this field are recommended to repeat this research in a wider community. It is also suggested that this research be carried out in other regions and provinces, by exercising more control over demographic characteristics (age, sex, type of thalassemia) and the results will be compared and the follow-up

phase will be taken.

The final results of this study showed that resiliency training and stress management skills increase the quality of thalassemic patients' life by group method. The reason for this is learning how to deal with the inevitable problems and difficulties of life and better coping with stress and unpleasant life events from the functional dimension.

A group of therapies for these patients is presented to express and share in individual experiences. The group can create space that, despite the denial and projection created by the disease, the developed healthy characteristics of disease be fertilized and the perceived stress is better managed. One of the benefits of attending in group meetings is to enable people to express their feelings and plans.

Most of the time, questions and answers are relevant to some important information about people and help them learn how to deal with the unpleasant feelings while expressing their feelings. Regarding the types of skills trained in the intervention group, the cognitive-behavioral stress management, including relaxation skill, learning various effective coping skills in dealing with stressful situations, managing anger and correcting the cognitive mistakes and cognitive distortions that in many cases are the source of negative thoughts and catastrophes. It seems they can increase the intervention of resiliency and management of cognitive-behavioral stress, the sense of personal control and the sense of adequacy and self-efficacy of the patient in the face of anxiety and stressful situations. In this way, it helps to improve the patient's quality of life. Also, the situation that the group provides for expressing emotions and expressing problems and concerns of the sick person in a similar way is not ineffective in this improvement.

According to the results of this study, the cognitive-behavioral therapy of stress and resiliency management is suggested as a selective and complementary therapeutic approach to the treatment of the psychiatric disorders in these patients and ultimately to increase the quality of their life.

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