Journal of Research in Medical and Dental Science
2019, Volume 7, Issue 2, Page No: 203-209

Available Online at: www.jrmds.in
eISSN No.2347-2367: pISSN No.2347-2545

The Relationship between Spiritual Well-being and Family Cohesion in Patients with Thalassemia Major

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ABSTRACT

Introduction: This study was conducted to investigate the relationship between spiritual well-being and family cohesion among people with thalassemia Major.

Methods: This cross-sectional study was conducted on 101 patients with thalassemia major of Dezful Large Hospital in 2015. Data were collected by three questionnaires: demographic data, Standard Spiritual Well-being Scale by Daaleman and Frey and Moos Family Cohesion Scale. The data was analyzed using SPSS version 18 statistical test, Pearson correlation and linear regression with a significance level of p<0.05.

Results: The average score of spiritual well-being and self-efficacy subscales were 9.66 ± 34.58 and 9.66 ± 14.68, respectively; which indicates the average level of these variables. Linear regression test results also showed that there was a statistically significant (p<0.05) relationship between spiritual well-being and family cohesion (B=0.25) and between self-efficacy and family cohesion (B=0.24); but there was no significant relationship between life scheme and family cohesion (B=0.16) (p=0.10).

Conclusion: In this study it was observed that a significant direct correlation exists between spiritual well-being and family cohesion. The role of the family as the main supportive institution against the challenges of life is undeniable. Hence, by increasing the level of spiritual well-being of the patients some steps can be taken to promote the cohesion of patients' families in order to decrease their spiritual and physical problems.

Key words: Spiritual well-being, Spirituality, Family cohesion, Thalassemia major

HOW TO CITE THIS ARTICLE: Yaghoob Madmoli, Malihe Salimi, Mostafa Madmoli, Narjes Davoodi, Fatemeh Rostami, Reza Heidari-Soureshjani, Najime Yousefi, The relationship between spiritual well-being and family cohesion in patients with thalassemia major, J Res Med Dent Sci, 2019, 7(2): 203-209

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Received: 20/03/2019
Accepted: 22/04/2019

INTRODUCTION

Thalassemia is a chronic disease [1], caused by the lack or deficiency of one or more polypeptide chains of hemoglobin, which is transmitted generation to generation [2]. The most severe form of this hematological disorder is beta thalassemia major [3,4]. The World Health Organization (WHO), introduced thalassemia as the most common chronic genetic disorder in 60 countries [2] that Iran is at of the high risk areas for the disease [3]. So that, according to the World Health Organization, 4 percent of the population of country is carriers of thalassemia and the number of patients with beta thalassemia major in Iran in 2013 were estimated more than 30 thousand people, while in a populated country like America it is less than 1000. Also, annually approximately 800 people are added to the population of patients with thalassemia [5].

Several reports worldwide indicate that life expectancy in patients with thalassemia is increased considerably and mortality rates significantly decreased with the help of available treatments [6-8]. However, social and psychological problems affect the quality of life in patients and their caregivers [8], more than 80% of people with Thalassemia Major (BTM) suffer from mental disorders [1,9], which produces a wide range of serious clinical and

psychiatric challenges for patients and their families [10]. Among the complications caused by the disease that affects patients' life include changes in bone, short stature, mental retardation [11,12], enlarged liver and spleen, heart failure [13-15], lack of physical growth and fertility [6] and premature death; that not only their physical performance is affected [11], but these can also affect their emotional and social performance [3].

Mental fatigue, well-being and educational performance issues [16], difficulties in playing social roles in society, the inability to raise a family [6], decreased self-esteem, reduced academic achievement [17], weak performance and ultimately low quality of life are the other problems caused by this disease [18]. In these patients, in addition to increased levels of stress [17] including physical and emotional stress, a significant financial stress also affects their families [19]. The patients suffering from BTM are faced to many challenges in which the role of families in providing different types of social support is of considerable importance [20]. This disease can make too much psychological burden for patients and their families [11,21]. Emotional distress, anxiety, fear, problems in dealing with the feelings of patients and its subsequent effects on the normal functioning of the family, are the common problems in families with thalassemia children [9,22].

Having a child with this disease may disrupt family dynamics and cohesion [23] Therefore, psychological support aimed at reducing emotional distress by parents, and strengthened coping strategies for everyday life's cohesion is required [24]. According to surveys, patients who received more social support from family and other people have had less depression [25,26]. Spiritual well-being is an important aspect of human health that the integrated relationship between internal forces and is determined by features like stability in life, peace, balance and harmony and a sense of connection and intimacy with God [27].

As a humanistic dimension of the individual, spirituality has an effective role in improvement and meeting the spiritual needs of patients and their families. Thus, it has gained increasing attention as an essential element of clinical care [28]. In case of disease, spiritual matters make a person to seek meaning and purpose of life, followed by increased spiritual needs [29]. Spiritual well-being is the core of human health, and fostering and promoting spiritual well-being can be a way of coping with the disease [30]. Research shows that religious beliefs may affect the overall health or coping with a disease [31,32]. Research conducted by Aydinok et al., showed that family awareness and psychological support leads to better compatibility of patients and reduces depression, obsession and paranoia [33]. Also, according to Kwong et al., the family functioning and social support can have many impacts on emergence of mental disorders or mental health of thalassemia patients [34].

Strengthening the spiritual dimension on the one hand reduces the symptoms of the disease and on the other increases a person's ability to adapt, it also improves mental health and helps to reduce feelings of hopelessness and depression and improves social performance [35]. Mcnulty et al. in a study among patients with multiple sclerosis (MS) found that spiritual beliefs and faith were helpful in coping with the disease [36]. Adegbola's study showed that the spiritual well-being of patients with sickle cell anemia is directly related to their quality of life [37].

Considering the effects of spirituality and dynamism and cohesion of the family in improving the symptoms, and due to the limited research done in this area, the present study was conducted to investigate the relationship between spiritual well-being and family cohesion in patients with thalassemia major in Dezful in 2015.

MATERIALS AND METHODS

This study is a descriptive analytical study that was conducted after obtaining the relevant permissions from ethics committee of Dezful University of Medical Sciences (DUMS-121) and the informed consent of patients with thalassemia referred to thalassemia major ward of Large Hospital of Dezful. Attainable sampling on eligible patients was used to select the participants. Overall, 125 patients referred to the center that 101 people participated with satisfaction in this study. Inclusion criteria included: patient satisfaction to participate, full awareness about the aims of the project, being literate, and having at least one record of hospitalization. And the exclusion criterion was incomplete questionnaire. Data collection tools included demographic questionnaire, Daaleman and Ferry Spiritual Index of Well-being (SIWB) [38] and Moos Family Cohesion Scale [39].

Demographic questionnaire included age, sex, body mass index, ethnicity, education level, occupation, marital status, monthly income, hospitalization record, and medication usage. SIWB scale is developed by Daaleman et al. [38] to measure the spiritual well-being and is the most famous spiritual well-being assessment scale and contains 12 questions that are designed based on Likert scale of five options. Total scores range from 12 to 60, the higher scores indicate higher spiritual well-being. It consists of two subscales of "self-efficacy" and "life scheme". Each subscale consists of 6 questions. A minimum of 12 and maximum of 60 points are possible that scores between 12 and 24 indicate low spiritual well-being of individuals, and scores between 24 and 36 represent average spiritual well-being and scores more than 36 show high spiritual well-being. In the initial measurement, Cronbach's alpha for the total scale, self-efficacy subscale and life scheme were 0.91, 0.86, and 0.89, respectively [38]. Family Cohesion Scale by Moos et al. [39] includes 9 questions. The range of scores are on two scales of completely true (0) and completely false (1). Reverse items of the questionnaire include items 1, 3, 4, 6, 8 and 9. The points are summed to calculate the total scores of people. The higher score indicates higher cohesion and coherence in a family environment. The minimum possible score was 0 and the maximum was 9 where the scores between 0 and 3 represent lower family cohesion, scores between 3 and 5 show average family

cohesion, and score higher than 5 shows good family cohesion.

In terms of correlation reliability, the researcher obtained the reliability of this questionnaire as 0.86 using test-retest and 0.78 through internal consistency [40]. To analyze the data SPSS software version 18 and independent t-tests, ANOVA, Pearson correlation and linear regression were used.

RESULTS

The sample included 101 patients with beta thalassemia major with an average age of 5.4 ± 23.22 years. Among these, 60.4% were male and the rest were female; and 82.2% were single, and the rest were married. Table 1 shows the demographics of the sample.

Table 1: Demographic characteristics of patients with beta-thalassemia

Item		Percent (%)	Relation with spiritual well-being	Relation with family cohesion
			p-value	p-value
Sex	Male	60.4	0.07	0.44
	Female	39.6		
Marital status	Single	82.2	0.31	0.1
	Married	17.8		
Place of residence	Urban	66.3	0.69	0.95
	Rural	33.7		
Level of education	Illiterate	2	0.83	0.58
	Under diploma	41.6		
	Diploma	38.6		
	Associate degree	3		
	Graduate and post graduate	14.9		
History of hospitalization	Yes	61.4	0.28	0.71
	No	38.6		
History of surgery	Yes	39.6	0.21	* 0.02
	No	60.4		
Blood type	A+	32.7	0.15	0.41
	A-	1		
	B+	23.8		
	B-	1		
	AB+	5.9		
	AB-	0		
	O+	35.6		
	O-	0		

*Significance level was considered under 0.05

Table 1 also shows that none of the demographic variables has a statistically significant relationship with spiritual well-being as well as family cohesion (p>0.05).

The average score of spiritual well-being and self-efficacy subscales were 9.66 ± 34.58 and 9.66 ± 14.68, respectively; which indicates the average level of these variables. The mean score of life scheme subscale is 19.8 that indicate its high level. The mean score of family cohesion is 4.63 that is at the average level (Table 2).

Table 2: Distribution of spiritual well-being, self-efficacy, life scheme and family cohesion in patients with beta-thalassemia

Variable	Categories	N (%)	Mean and SD
Spiritual well-being	Low	15.8	34.58 ± 9.66

	Average	45.6	
	High	38.6	
Self-efficacy	Low	44.6	14.68 ± 6.71
	Average	22.7	
	High	32.7	
Life scheme	Low	10.9	19.8 ± 5.84
	Average	30.7	
	High	58.3	
Family cohesion	Low	30.7	4.63 ± 1.81
	Average	38.6	
	High	30.7	

Surgery record and family cohesion has a statistically significant relationship (p=0.02). Thus, those who had surgery had less family cohesion. Other statistical relationships are shown in Table 1.

Linear regression test results also showed that there was a statistically significant (p<0.05) relationship between spiritual well-being and family cohesion (B=0.25) (p=0.009) (Figure 1) and between self-efficacy and family cohesion (B=0.24) (p=0.01); but there was no significant relationship between life scheme and family cohesion (B=0.16) (p=0.10).

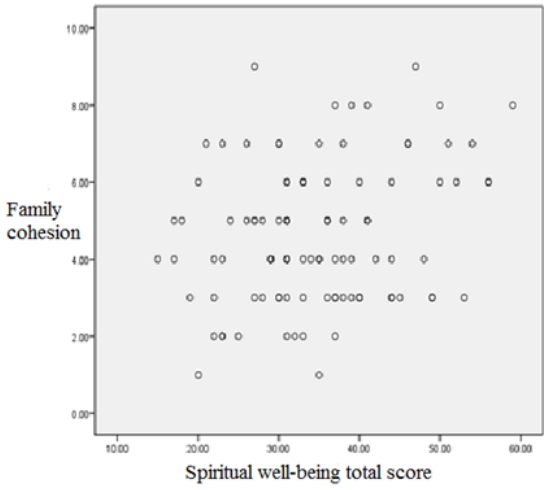

Figure 1: Correlation between spiritual well-being and family cohesion in patients with beta-thalassemia (p=0.009) (r=0.25)

DISCUSSION

Spirituality is one of the important dimensions with a high impact on people's lives and it includes many personal and social functions [41]. Spiritual achievements in health care have a huge appeal because research has confirmed its potential effect in the prevention, response to or recovery of disease [42]. The total score of spiritual well-being in patients with BTM was obtained as 34.58 ± 9.66 that shows an average level of spiritual well-being in the patients, meanwhile the level of spiritual well-being in dialysis patients is low (13.21) [43]. However, Balboni et al. state high level of spiritual well-being in patients with advance cancer [44].

In this study, self-efficacy subscale score was 14.68 which indicate the average level of this variable. While Sheibani et al. point out the low level of self-efficacy in adolescents with thalassemia [45]. Family cohesion's mean score was 4.63 which are at the average level that indicates the need to more institutions which increase family cohesion for patients [9].

In this research, family cohesion has been at an average level. Children with thalassemia compared to healthy children have lower quality of life in all aspects that affect the family cohesion [16]. Other studies also support the low quality of life of these children that is the result of factors such as family income, family education regarding the view toward the thalassemic patients that improve patient's performance [9].

The present study aimed to investigate the relationship between spiritual well-being and family cohesion in patients with thalassemia major. It was observed that a significant correlation exists between spiritual well-being and self-efficacy with family cohesion and patients who had higher spiritual well-being also experienced higher self-efficacy, coherence and family cohesion. In this regard, the study by Viola et al. in Italian Never-Employed Young Adults in 2017 showed that significant positive correlation exists between spiritual well-being and self-efficacy [46]. de Mamani et al. study found that promotion of spirituality will strengthen family cohesion and their compatibility [47]. Mohammadi et al. study on young people with thalassemia major [48] and Adegbola's study in on patients with sickle cell anemia [37] showed that spiritual well-being increases by higher quality of life of patients. Balboni et al. study on patients in the final stages of life also showed that patients who had higher mental health had less feelings of hopelessness [49]. However, Bussing et al. study on patients with cancer showed moderate correlations between spiritual well-being and quality of life [50]. These results could be evidence of a significant relationship between spiritual well-being and various

aspects of human life. Spiritual beliefs are an important part of family life in all communities [41].

Spiritual well-being is an ambiguous and complex process of human evolution that provides a harmonious relationship between internal forces [51]. In this study, the total score of spiritual well-being in patients with thalassemia was obtained 9.66 ± 34.58, indicating a moderate level of spiritual well-being in these patients. Patients had moderate spiritual well-being in Mohammadi et al. study on young people with thalassemia major, Nsamenang et al. study on patients with multiple sclerosis [48,52]. While, Ebrahimi et al. found that the level of mental health in hemodialysis patients was low (10.20), respectively [43] and in a study by Balboni et al. on patients with advance cancer, a high level of mental health was reported [44]. In the present study, no significant relationship between sex and spiritual well-being was found (p=0.07) that is in line with Bussing et al. [50]. In the present study, no significant relationship between education and spiritual well-being was found. However, the study by Hasanshahi et al. concluded that teaching spirituality is an important factor in promoting spiritual well-being [41].

CONCLUSION

According to findings it can be concluded that spiritual well-being has a significant role in consistency and cohesion of families of patients with thalassemia major. Given that the health care of these patients impose heavy costs on families and having children with such a disease in the family influences family cohesion, it is suggested that public health officials plan training programs to strengthen the spiritual well-being of these patients and their families, because by increasing the levels of spiritual well-being of the patients they take steps to promote family cohesion which has a significant role in reducing the patient's mental and physical problems. Meanwhile, family cohesion, and spiritual well-being of these individuals play an important role in predicting their efficacy. Therefore, health system planners should pay special attention to developing educational programs for these patients.

The major limitation of this study was to collect data at one period of time, excluding the illiterate and the limited number of previous studies on patients with thalassemia major. To further explore the relationship between spiritual well-being and the family cohesion it is recommended that more studies are done in this area.

ACKNOWLEDGMENT

Researchers express their appreciation and thanks to the patients with thalassemia, nurses and personnel of Thalassemia major ward, authorities of Dezful Large Hospital, deputy and personnel of Dezful University of Medical Sciences.

CONFLICT OF INTEREST

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

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