



Quality of Self-Care in Adolescents with Major Thalassemia Referred to Selected Thalassemia Centers in Iran

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ABSTRACT

Aims Adolescents who suffer from chronic diseases, such as major thalassemia are more susceptible to physical, mental, emotional, spiritual, educational, and social self-care failure. These factors are generally more likely to be overcome if affected adolescents have a high level of self-care. This study aimed to assess self-care quality in adolescents with major thalassemia.

Instrument & Methods This descriptive cross-sectional study was performed on 200 adolescents with major thalassemia selected by convenience sampling. The Self-Care Assessment Questionnaire (SCAQ) with 52 items in six dimensions was used for data collection. Data were analyzed using descriptive statistics, independent t-test, Pearson correlation coefficient, and ANOVA.

Findings There was no significant relationship between socio-demographic characteristics and the dimensions of self-care in participants. Adolescents with major thalassemia were found with a high score of quality of self-care. The highest mean scores were related to the dimensions of "emotional/mental self-care (2.44±0.64)", "social self-care (2.08±0.61)", and "spiritual self-care (2.07±0.62)", respectively.

Conclusion It is recommended that this issue be investigated in other adolescent patients, considering the importance of self-care and its effects on various aspects of quality of life in chronic diseases. Also, planning and implementing patient education is another important management measure to promote self-care in these adolescents.

Keywords Self-Care; Adolescence; Thalassemia

CITATION LINKS

[1] Assessment of haematological parameters ... [2] Impact of burden of thalassemia major on ... [3] β -Thalassemia in Iran: Things everyone ... [4] Self-efficacy of adolescents with thalassemia ... [5] The study of self-care agency in patients ... [6] Health literacy, self-efficacy, and self-care behaviors ... [7] Selfcare behaviors of African American women living ... [8] Linking nursing care interventions with client outcomes: ... [9] Reflecting on a self-care process in the home setting for ... [10] The influence of chronic illness and lifestyle behaviors ... [11] Essential Pediatric ... [12] Self-care in adults with sickle cell ... [13] Cardiovascular disease self-care ... [14] Transforming the pain: A workbook on vicarious ... [15] Relation social support and psychological well-being among schizophrenic ... [16] Exploring self care in Tehran, Iran: ... [17] Assessment of procrastination in providing nursing ... [18] Validity and reliability in social science ... [19] The impact of self-care education based on Orem's model on self-care ... [20] The effect of health promoting education plan on adolescents' lifestyle ... [21] Quality of life in children with β -thalassemia major at ... [22] Self-care ability in hemodialysis ... [23] Effects of home-care training on the self-efficacy of patients ... [24] A middle-range theory of self-care of ... [25] Investigating the awareness and educational requirements of adolescents with thalassemia and active members ... [26] Effect of a mobile-phone mediated based education on self-care behaviors ... [27] The effect of orem self-care on mental health of ... [28] Psychological problems and quality of life in children ... [29] Self-care in patient with major thalassemia: A ... [30] Illness knowledge, social support and self care behavior in adolescents with ... [31] I. of our spiritual ... [32] The effect of spiritual intelligence training on the hope ... [33] The impact of spiritual self-care education on self-efficacy in adolescents with Thalassemia ... [34] Meta-analysis of efficacy of interventions for elevated ... [35] A critical review of a spirituality ... [36] Effect of spiritual care on hope and self-transcendence of mothers of premature ... [37] Hope, the foundation of spiritual health in adolescents: A ...

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Introduction

Thalassemia is a hereditary condition that is passed down from parents. There are two primary forms of thalassemia: alpha thalassemia and beta thalassemia. In cases where four genes for alpha globin or two genes for beta-globin are missing, varying degrees of alpha- and beta-thalassemia always occur. Alpha thalassemia is one of the most common hereditary blood problems at the international level, which is the result of the absence or reduction of globin chain production. Beta-thalassemia is the most common and uncommon site for persistent hemolytic anemia among young adults worldwide. The global annual occurrence of symptomatic sufferers is anticipated at one in 100,000 [1, 2].

Based on the latest census, which was taken in 2018, the Iran population is reported around 81 million persons, of which 4% are carriers of the beta-thalassemia genes [3]. These patients require being cared for always and need daily care, such as regular blood transfusions and iron chelation.

Major elements affecting the disorder's development are useless hematopoiesis, hemolysis, and anemia. Physical issues, such as persistent anemia, bone deformities, developmental changes, and early maturation on the one hand, and long and frequent medical procedures affect the exceptional existential components of young people [4].

While adolescence is a dynamic period of transition from youth to personal maturity—a time of profound biological, heady, psychosocial, and financial change—this part of rapid two-dimensional prosperity and recovery is the easiest phase of existence. During this process, people develop through stages of bodily and sexual maturity, steadily increase greater state-of-the-art highbrow and reasoning capabilities, and make essential social, emotional, educational, and occupational choices to in the long run form their careers and fitness outcomes [4].

Thalassemia causes these patients to suffer from fatigue, some degree of anemia, and a lack of tolerance toward physical activities [1]. In addition, bone marrow hyperactivities cause visible changes in the face and skull bones that may be seen in these patients. In addition, they may experience growth failure, bone tissue loss, and an enlarged liver, which are common.

The most important factor underlying the effects of such disorder is a lack of self-care activities, such as physical, emotional, spiritual, educational, psychological, and medical self-care [5]. Thalassemia can cause a reduction in the quality of life and self-care ability in affected patients [6].

Self-care behaviors are affected by various factors, such as experience, education, culture, scientific knowledge, learning, gender, and race [7]. Self-care behaviors occur within the context of ongoing care, which will support life and healthy functioning. In the

process of self-care, an individual's engagement in self-care behaviors is linked to the prevention of complications [8]. Nursing research has shown that self-care changes over time and is dynamic [9].

The presence of chronic illness is related to unhappiness and psychological distress, leading to a low quality of life [10]. Because thalassemia major is chronic hemolytic anemia, the nurse must maintain close contact with the adolescent for continued care. The nurse must meet the all needs of the adolescent and his/her family [11]. Therefore, promoting self-care has become a central concern for nurses, patients, and their parents [12].

Self-care is one of the most important research priorities in the field of nursing care in chronic disease. Therefore, the National Institute of Nursing Research places great emphasis on symptom self-management in chronic patients [13].

Since self-care is an essential component of the long-term management of chronic illnesses, it is important to address this important issue to receive more accurate information about self-care status in adolescents with major thalassemia and to carry out interventions and subsequent treatment plans. Therefore, the researcher decided to investigate the quality of self-care in these patients, especially in adolescents, who are demanding independent behaviors in their lives.

Instrument and Methods

Study design and setting

This cross-sectional descriptive quantitative study was performed on adolescents with major thalassemia referred to selected hospitals and centers in Tehran, Iran, from February to May 2021. These educational centers affiliated with the two universities of medical sciences are considered the main centers for referring and treating patients with thalassemia in Iran with clinics for thalassemia patients and inpatient wards.

Participants and procedures

The participants were selected by convenience sampling. The sample size was obtained according to the following formula, and considering 10% loss (incomplete questionnaires), 200 samples were considered.

$$n \geq \left[\frac{(z_{1-\alpha/2} + z_{1-\beta})}{0.5 \times \ln[(1+r)/(1-r)]} \right]^2 + 3$$

$$r = 0.25$$

$$\alpha = 0.05 \Rightarrow z_{1-\alpha/2} = 1.96$$

$$\beta = 0.10 \Rightarrow z_{1-\beta} = 1.28$$

All participants aged 11-20 years old, had at least one history of blood transfusion at the thalassemia center and had no other complications, and those who were unable to hear and speak in the Persian language were excluded.

After explaining the objectives and methods of the research, the questionnaires in the Persian language

were given to the subjects. For the illiterate cases, the items were read by the researcher and their responses were marked. The response time to complete the survey was 20-25 minutes.

Research tools and measures

Socio-demographic information checklist: This checklist Included age, age at the onset of the disease, gender, place of living, economic status, mother's and father's job, mother's and father's education level, childbirth rank, the number of children in the family, having a sibling with thalassemia, family status, the adolescent's education level, medical history in adolescents, the history of surgery, blood transfusion interval, type of blood product, and the time of the first injection.

Self-Care Assessment Questionnaire (SCAQ): SCAQ was made by Saakvitne and Pearlman (1996) [14], to evaluate factors of self-care, such as physical self-care (11 items), emotional/mental self-care (12 items), social self-care (nine items), spiritual self-care (nine items), professional self-care (eight items), and practical self-care (three items). Regression analysis was applied to figure out the influence of exogenous variables on endogenous variables and examine the influence model among variables [15]. First, the SCAQ was translated from English to the Persian language by the forward-backward method [16]. This questionnaire contains six dimensions and 52 items reflecting the actions of the person in self-care, based on a five-Likert scale from one (always) to five (never). The minimum and maximum scores are 52 and 260. The higher score indicates better self-care.

Validity and reliability

The qualitative face validity was assessed by the judgment of ten selected adolescents in a targeted manner. Also, the qualitative content validity regarding the clarity, relevancy, and adequacy of items was assessed by the judgment of ten faculty members of Shahid Beheshti University of Medical Sciences and experts in the field of child and adolescent [17, 18]. The reliability of the instrument was determined through Cronbach's alpha ($\alpha=0.91$).

Data analysis

Data were analyzed by SPSS software 26. The descriptive statistics (frequency and percent) described the socio-demographic and clinical characteristics. The independent t-test, Pearson Correlation coefficient, and ANOVA were applied for the data analysis and p-values less than 0.05 were considered significant.

Findings

Most adolescents with major thalassemia (55.5%) were girls. Also, 55.0% aged 18-20 years old. Other demographic characteristics are shown in Table 1. The mean scores of all self-care dimensions (physical self-care, emotional/mental self-care, social self-care, spiritual self-care, professional self-care, and practical self-care) are reported in Table 2.

Table 1. Socio-demographic and clinical characteristics of participants (n=200)

Demographic variable	Frequency (percent)
Age (year)	11-14
	15-17
	18-20
Gender	Female
	Male
Place of living	City
	Village
Age at diagnosis (year)	< 1
	1-3
	> 3
The first injection time (year)	< 11-3
	37(18.5)
	> 3
Economic status	Poor
	Moderate
	Good
Father's education	Bachelor's degree and above
	Diploma
	Under diploma
Mother's education	Bachelor's degree and above
	Diploma
	Under diploma
Childbirth rank	First
	Second
	Three or more
Number of children in the family	1
	2
	3
	Four or more
Adolescent's education level	Dropout
	Primary
	Secondary
	High school and above
Father's job	Employee
	Non-governmental
	Unemployed
Mother's job	Employee
	Housekeeper
	Others
Family status	Living parents
	Deceased parent
	Parents divorced
Having a sibling with thalassemia	Yes
	No
Medical history	None
	< 5 signs
	> 5 signs
History of surgery	None
	Liver
	Heart
	Spleen
Type of blood product	Compressed red blood cells
	Other products
Family members with thalassemia	Yes
	No
Adolescent's education	Grade point average above 15
	Grade point average under 15
Blood transfusion intervals	Once a month
	Twice a month

Table 2. The mean scores of the self-care dimensions in participants

Dimension	Mean± standard deviation
Physical self-care	1.81±0.55
Emotional/mental self-care	2.44±0.64
Social self-care	2.08±0.61
Spiritual self-care	2.07±0.62
Professional self-care	1.92±0.56
Practical self-care	1.30±0.49
Total self-care	2.03±0.46

Table 3. Relationship between demographic characteristics and self-care dimensions in participants

Variable	Statistics	Physical Self-care	Mental/emotional Self-care	Social Self-care	Spiritual Self-care	Professional Self-care	Practical Self-care	Self-care
Age	r	0.055	0.031	0.043	-0.053	0.091	-0.004	0.039
	p-value*	0.439	0.661	0.541	0.455	0.199	0.961	0.588
Age at diagnosis	r	0.06	0.017	0.107	0.074	0.044	0.064	0.075
	p-value*	0.398	0.811	0.13	0.301	0.54	0.368	0.291
Age at the disease onset	r	0.04	0.014	0.108	0.076	0.046	0.033	0.068
	p-value*	0.569	0.847	0.129	0.284	0.515	0.638	0.337
Economic status	F	2.389	1.276	0.654	0.769	0.34	1.132	1.438
	p-value**	0.094	0.281	0.521	0.465	0.712	0.324	0.24
Father's educational level	F	0.345	1.096	0.265	1.18	0.974	2.76	0.851
	p-value**	0.708	0.336	0.767	0.309	0.38	0.066	0.428
Mother's educational level	F	0.523	0.055	0.266	1.035	0.249	2.377	0.115
	p-value**	0.593	0.946	0.767	0.357	0.779	0.095	0.892
Birth rank	F	1.205	0.234	2.121	0.844	0.332	0.097	0.94
	p-value**	0.302	0.791	0.123	0.432	0.718	0.908	0.393
Number of children	F	1.145	0.933	2.129	1.206	0.473	0.144	1.127
	p-value**	0.332	0.426	0.098	0.309	0.701	0.934	0.339
Adolescent education level	F	0.653	0.901	1.5	1.971	0.162	0.165	1.143
	p-value**	0.582	0.442	0.216	0.12	0.922	0.92	0.333
Father's Job	F	2.058	1.059	0.367	0.18	0.234	0.448	0.719
	p-value**	0.13	0.349	0.693	0.836	0.791	0.64	0.488
Mother's job	F	0.041	0.907	0.54	0.442	3.09	4.916	0.457
	p-value**	0.96	0.405	0.584	0.643	0.048	0.008	0.634
Family status	F	1.457	0.336	0.271	0.028	0.32	1.027	0.302
	p-value**	0.235	0.715	0.763	0.973	0.726	0.36	0.74
Medical history	F	1.811	1.199	1.333	1.87	3.936	0.037	0.106
	p-value**	0.166	0.304	0.266	0.157	0.021	0.964	0.899
History of surgery	F	0.972	1.237	0.421	0.411	0.509	0.607	0.854
	p-value**	0.407	0.298	0.738	0.745	0.677	0.611	0.466
Type of blood product	F	0.542	0.287	0.59	1.027	0.147	1.003	0.335
	p-value**	0.583	0.751	0.555	0.36	0.864	0.369	0.716

*Pearson correlation coefficient; **One-way ANOVA.

The results of the independent samples t-test indicated no significant relationship between gender ($p=0.07$), place of living ($p=0.71$), having a sibling with thalassemia ($p=0.36$), adolescent's education ($p=0.06$), and blood transfusion intervals ($p=0.20$) and self-care. Furthermore, there was no significant correlation between the other demographic characteristics and self-care among adolescents. However, one-way ANOVA results showed a significant relationship between the mother's job and two dimensions of "professional self-care" and "practical self-care". In addition, a significant relationship was observed between disease history and professional self-care dimension (Table 3).

Discussion

The main objective of this study was to evaluate the quality of self-care among adolescents with thalassemia referred to educational hospitals and thalassemia clinics. The results showed a high level of self-care in adolescents with major thalassemia.

According to the results of the present study, the adolescents had a high level of physical self-care. In other words, adolescents with thalassemia have paid special attention to their physical needs and special care in accordance with their age, which is in line with the results of Masinaienejad *et al.* [19], Arazi *et al.* [20], Kaheni *et al.* [21], and Atashpeikar *et al.* [22]. In these studies, the quality of physical care in the participants was above average and acceptable. In contrast, other

studies have shown that the quality of physical self-care in patients with major thalassemia was low and somewhat neglected, such as in the study by Moghadam *et al.* [23]. The destructive effects of chronic diseases that cause significant physical changes in the affected person [24], and lack of awareness of such changes and the need for physical care [25], change the feelings of a person with thalassemia toward his/her body and reduce sensitivity in their care. However, if a person's understanding of the severity of the disease and possible side effects and benefits of managing self-care behaviors [26] increases, it can significantly help improve the quality of physical care.

However, the results of the present study indicated a high quality of mental/emotional self-care in participants with thalassemia, which is consistent with the results of Madmoli *et al.*, who investigated the effect of the Orem self-care model on the mental health of patients with thalassemia [27]. After teaching Orem self-care to thalassemia patients, a significant improvement was observed in mental health, emotional well-being, reduction of mental fatigue, and quality of life. In addition, several studies have reported a high quality of mental health in thalassemia patients [20, 21]. Also, in the study by Masinaienejad *et al.* [19], the self-care behaviors of patients with beta-thalassemia improved after self-care training in the mental health dimension. However, the results are not the same in all studies

[23]. In other words, psychological problems, such as anxiety and depression in thalassemia patients reduce mental well-being, which predicts an impairment in their quality of life [28]. Therefore, there is a need to set up support systems, such as psychological counseling programs in thalassemia clinics.

In contrast, some patients redefine the disease in the process of improving their quality of life and acquiring a new identity. They are more likely than others not only to accept the disease but also to see its consequences as an opportunity for change and success [29].

The participants in the present study had a high quality of social self-care. In other words, these adolescents could maintain their activities in social affairs and establish a high quality of care by establishing appropriate communication with friends and important people in life. In this regard, Yang *et al.* introduced the family as the most important source of social support in adolescents with thalassemia. Social acceptance of adolescents by their friends and peers indicates good social support [30]. Furthermore, based on the findings of previous studies, it is recommended that more psychosocial support be provided to patients with thalassemia.

In the present study, the participants had an acceptable quality of self-care in the spiritual dimension. This is consistent with the results of Du Bois WE [31], who showed the high quality of spiritual self-care in chronic patients. Despite the known effect of spirituality on the level of physical and mental health [32], some studies are inconsistent with the results of the present study. For example, Iri *et al.* used spiritual self-care education as a therapeutic intervention in adolescents with thalassemia and reported conflicting results obtained. Participants' self-efficacy in self-care remained weak even after the intervention [33]. Other studies have shown the slight effect of spiritual care and its interventions on individuals [34, 35]. In comparing the results, the heterogeneity of factors, such as age, education, socioeconomic status, and support of others should be considered.

In addition, social and cultural context and religious beliefs play an important role in spiritual care [36, 37]. Because culture has an important role in the formation of beliefs, determining methods for understanding stressful situations, and positive progress in the heart of a critical situation. In addition, adolescents are exposed to the challenges of adolescence, which leads to identity disorders and adaptation to existing conditions. All these issues can affect the rate of growth and changes in spiritual issues in adolescents with thalassemia. Therefore, the discrepancy in the results of different studies is predictable.

The participants of the present study were found with acceptable professional self-care. This result is consistent with the results of Atashpeikar *et al.* [22],

who indicated that hemodialysis patients generally behave professionally in self-care situations. Also, Masinaienejad *et al.* evaluated the impact of Orem-based self-care education on self-care behaviors in four aspects, including therapeutic measures, nutrition, physical activities, and mental health in patients with beta-thalassemia. This educational intervention was effective in three aspects of self-care behaviors, including therapeutic measures and their mean scores were significantly different after the intervention [19]. Patients' better performance in professional self-care can be explained by the fact that during chronic diseases, a person faces many challenges and gradually tries to solve situations learns from experiences, and develops the skills acquired in this way to enjoy better self-care.

Our adolescents with thalassemia obtained an acceptable average score of practical self-care, which is consistent with the study by Atashpeikar *et al.* [22] who showed a high quality of care in all dimensions, especially practical self-care in all participants. This means that improving all aspects of self-care is important and a lot of effort has gone into achieving it. Patients with thalassemia need ongoing care to cope and reduce complications. They should also have a normal life with daily and dynamic events.

Limitations: The difference in language between the first researcher (a student from Iraq) and the patients caused no proper communication with patients and the COVID-19 pandemic caused problems in collecting samples. Also, the center had a lot of sensitivities towards its own teenage patients and as a result, it has issued sampling permission late, and also some centers refused to collect samples.

Conclusion

The results of this study showed that adolescents with thalassemia, despite all the difficulties and consequences of the disease are successful in self-care in all dimensions of physical, mental, social, professional, and practical. This result indicates the appropriate coping of these adolescents with the disease, which in turn can pave the way for the formation of a clear identity, increase self-confidence and empowerment, increase self-efficacy, and, consequently, improve and enhance the quality of life in these adolescents. Based on these results, it is recommended to research the quality of self-care in adolescents with other chronic diseases.

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Ethical Permissions: This study was approved by the Committee of Ethics in Biomedical Researches of Shahid Beheshti University of Medical Sciences (IR.SBMU.PHARMACY.REC.1399.318). All methods were performed in accordance with the declaration of Helsinki. After explaining the objectives of the research, written

informed consent was obtained from all participants. For participants under age 16, it was obtained from their parent or legal guardian. Informed consent was obtained from their next of kin/legally authorized representative for illiterate participants. The subjects were also ensured of the confidentiality of data and made aware of the right to withdraw from the study.

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