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A comparative study of body image in adolescents with beta-thalassemia major and healthy individuals

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ABSTRACT

Background and Objective: Physical abnormalities in patients with beta-thalassemia major might potentially have a negative impact on the patient's body image (BI). The aim of the current study was to evaluate the BI of adolescents with thalassemia in Southeast Iran in comparison with healthy peers.

Methods: This cross-sectional study was performed on 94 individuals in Ali Asghar Hospital in Zahedan in 2020. A total of 46 teenagers with beta-thalassemia major and 48 healthy individuals, both groups in a range of 11-18 years of age, were entered into the study. Evaluation of the BI was performed by using the Multidimensional Body-Self Relations Questionnaire (MBSRQ). All statistical analyses were performed by SPSS-22 software. Obtained data were displayed by using descriptive statistical methods. Independent t-test and ANOVA were applied to compare the scores of different groups. The P values less than 0.05 were considered statistically significant.

Findings: The statistical analyses revealed a significant difference in the appearance evaluation, fitness evaluation, fitness orientation, and body areas satisfaction scales, with a higher score of the thalassemia patients group in the first three items, ($p<0.05$). The difference between the two groups was not significant in appearance, orientation and subjective weight scales ($P>0.05$).

Conclusion: An unfavorable BI in adolescents with thalassemia, as a kind of psychiatric disorder, emphasizes the need for emotional and social supports by family, medical staff and peers.

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Introduction

The term "Body Image" (BI) was first coined by Paul Schilder in the mid-1930 and is defined as "the picture of our own body which we form in our mind, that is to say, the way it appears to ourselves". This definition of BI which focuses on physical appearance was then expanded by other researchers [1]. Sarwer and Cash believed that BI is a multidimensional perception, composed of perceptual, attitudinal and behavioral dimensions [2]. BI is not associated with one's actual appearance, but with his/her beliefs, perceptions, thoughts, and emotions regarding his/her body [3].

Physical appearance is the first contributing factor in making a first impression. Most people -especially teenagers and the youth- pay particular attention to their appearance and how it might socially affect them. They may spend a lot of time and money on altering their appearance to present their body in the best way they can [4, 5], a concept that might be extended throughout their entire lifespan [6]. Now, what about people with different appearances? Do they encounter challenges?

Thalassemia major is one of the problems of our society today and many countries around the world. Due to the disruption in the production of globin chains in the structure of hemoglobin, the resulting red blood cells in the bloodstream do not have a normal life and die quickly. The chronicity of this disease and the need for lifelong treatment lead to a negative impact on the physical and mental health of these children. As a chronic disease which causes physical abnormalities, thalassemia major drastically influences the patients' appearance. Excessive consumption of energy and calories for hematopoiesis leads to physical weakness and excessive susceptibility to infections. Without treatment children with B-thalassemia major usually become symptomatic from anemia. Profound weakness and cardiac decompensation follow, and given the extent of their impaired HbF production regular transfusions will be necessary by 2nd year of life [7].

The most important principle of treatment is regular blood transfusion to counteract the anemia as it causes many complications such as reduced growth, increased bone marrow activity and as a result bone changes and enlargement of the liver and spleen [8]. Skeletal malformation as the result of extramedullary hematopoiesis, hepato-splenomegaly, growth retardation and delayed or a total lack of puberty, causes physical malformation of the body, altering the appearance [9]. This alteration significantly affects the BI of a patient, which in turn, can have a negative impact on self-esteem [5]. Patients with this chronic illness feel different and their fear of rejection leads to problems in their social interactions [10]. It is difficult for the patients to accept their illness as a part of their identity. These challenges are much more apparent in the adolescence stage, in which the teenagers are faced with several concerns such as leaving the world of childhood, experiencing puberty, identity formation and the need for independence [11, 12].

The aim of the current study was to evaluate the BI of adolescents with thalassemia in Southeastern Iran and compare them with their healthy peers.

Methods

Subjects

This case-control study is performed on 94 individuals in Ali Asghar Hospital in Zahedan in 2020. We study 46 thalassemia major patients, in our case group and 48 healthy individuals in our control group. For our cases group, we gathered the data and information of Thalassemia patients who were registered at Ali-Asghar Hospital in Zahedan over 1 year. These patients came in regularly for check-ups and after obtaining their consent during one of these visits we selected them for the study. For the control group, we asked the individuals who companied the thalassemia patients for their consent and further documented their health status to ensure their well-being in the absence of a chronic illness.

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Eligible criteria: All patients' ages range from 11 to 18 years old, as this is seemingly the range in which individuals are most obsessed with their looks. 18 years is the maximum age after which one enters adulthood. We match the individuals in our control group with those in the case group in regards to their age and gender. The patients we enrolled in the study were already diagnosed with beta-thalassemia major by a pediatric hematologist via a blood sample undergone electrophoresis to detect abnormalities within the beta chain (as is with the pathophysiology of beta-thalassemia) [13]. All the patients in this study expressed their consent to participate. Exclusion criteria: Patients who had been successfully treated with bone marrow transplants, as well as patients who did not want to complete the questionnaire were excluded from the study. Following necessary clarifications, all participants were asked to fill a standard questionnaire carefully. Data including age, sex, history of heart disease, diabetes mellitus, hepatitis B and the details of their puberty were obtained through physical exams and detailed medical histories which we recorded in their medical documents.

Multidimensional Body-Self Relations Questionnaire (MBSRQ)

MBSRQ is a self-assessment scale, made by Cash, Winstead & Janda in 1986. The present study used the final version provided by Cash in 2017. [14] It includes 6 subscales including Appearance Evaluation (AE), Appearance Orientation (AO), Fitness Evaluation (FE), Fitness Orientation (FO), Subjective Weight (SW) and Body Areas Satisfaction (BAS). The questionnaire was intended for patients within this range and was filled out by the patients themselves. A total of 46 items, each measured on a five-point scale scoring from 1 to 5 (higher scores indicate a worse BI), were provided in this questionnaire. In the ongoing study, the reliability of the test was 0.32, 0.58, 0.56, 0.60, 0.79, 0.86 and 0.67 for AE, AO, FE, FO, SW and BASS scales and the whole questionnaire, respectively. The Cronbach's alpha coefficient was applied in this study to calculate the reliability of the test.

Data Analysis

The obtained data were shown by using descriptive statistical methods. Independent t-test and ANOVA were used to compare the scores of different groups. The P values less than 0.05 were considered as statistically significant. All statistical analyses are performed by SPSS-22 software.

Results

A total of 46 teenagers, 25 males and 21 females, with established β-thalassemia major registered with Ali Asghar hospital in Zahedan, and a control group of 48 healthy individuals, 24 males and 24 females were included in the present study.

The case group was complicated by several problems. Among the 46 patients in this group only three males (12%) and three females (14.3%) had experienced puberty; the remaining 40 patients had not reached their puberty yet even though they fell into the same range of age (i.e. 11-18 years old). Note that in the table1, it is illustrated that the patients have not achieved puberty, but the number of those who have achieved puberty was only mentioned. Cardiac complications were detected in 20 (43%) patients. Two females also had diabetes mellitus and three individuals were hepatitis B virus (HBV) positive. Complications observed in the case group are shown in table 1, categorized by the conditions seen in each gender, and a total regardless of gender.

The BI, evaluated by the scores of the Multidimensional Body-Self Relations Questionnaire, was compared between the case and control groups, as represented in table 2. The results of the independent t-test revealed that there was a statistically significant difference in the Appearance Evaluation, Fitness Evaluation, Fitness Orientation, and Body Areas Satisfaction scales between thalassemia patients and control groups. It should be noted that the scores of Appearance Evaluation, Fitness Evaluation and Fitness Orientation scales were higher in the thalassemia patients group, while the healthy group had an overall higher score for the Body Areas

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Satisfaction scale. The statistical analyses suggested no existing significant differences in the Appearance Orientation and the Subjective Weight scales between the two groups (P>0.05).

Table 1. The complications observed in the thalassemia patients group

Complications	Males (n=25) Frequency (%)	Females (n= 21) Frequency (%)	Total (n=46) Frequency (%)
Lack of puberty	22 (88)	18 (85.7)	40 (87)
Cardiac complications	5 (20)	15 (71.4)	20 (43)
Diabetes mellitus	-	2 (9.5)	2 (4)
HBV*	1 (4)	2 (9.5)	3 (6)

* Hepatitis B virus

Table 2. Body-image comparison between thalassemia patients and control groups based on independent t-test

Criteria	Thalassemic Group			Control Group			P-value
	N	Mean	SD	N	Mean	SD	
Appearance Evaluation	40	15.52	3.471	44	13.45	4.385	0.01
Appearance Orientation	40	26.42	6.827	40	27.65	5.802	0.39
Fitness Evaluation	42	10.83	3.282	46	9.39	3.393	0.05
Fitness Orientation	34	35.52	4.507	44	32.36	8.035	0.03
Subjective Weight	46	5.45	1.797	48	5.93	1.730	0.19
Body Areas Satisfaction	42	32.69	6.311	45	36	6.134	0.01

Discussion

The result of the present study showed an unfavorable BI in adolescents with thalassemia, which as a kind of psychiatric disorder, emphasizes the need for emotional and social supports by their families, medical staffs and peers. [7]. As stated in the introduction, the skeletal malformation as the result of extramedullary hematopoiesis, hepato-splenomegaly, growth retardation and delayed or lack of puberty, alters the patients' appearances [9]. The resulting different appearance might potentially affect the BI of the patient.

Diagnosis of a chronic illness is a disastrous and devastating experience, which imposes psychosocial and emotional problems on the patients and their families [15]. According to the studies, there is an established association between appearance and self-concept. Studies suggest that persons with a visible body disfigurement have a negative self-image and subsequently lower self-esteem [5]. Several studies assess the BI of patients with different chronic conditions. Yu Fan and Eiser published a systematic review evaluating the BI of children and adolescents with cancer. A study suggested that an unfavorable BI had a negative impact on self-esteem and put the patients at a higher risk of psychiatric disorders including anxiety and depression. It was noted that social supports could help patients by attenuating such problems. However, they found no consistent evident indicating that BI in cancerous children and adolescents was worse than their healthy counterparts [16]. A study by Sohinda et al. in 2019 displayed that self-esteem was associated with BI, and low self-esteem was strongly associated with negative BI [17].

Other studies have found results in direct correlation with ours. A study in Tunisia reflects on the academics and the psycho-social consequences of thalassemia patients. It is stated, in the study, that the condition has debilitating effects on the patient's physical activity, social integration, academics results and emotional life [18]. Thalassemia Major and its effect on socio-religious status have also been the aim of a large study in Pakistan. The study on 932 familial marriages and 197 non-familial marriages states lack of knowledge and patriarchy as contributing factors to the prevalence of inadequate information, stigmatization and superstitions as impactful factors on thalassemia patients [19].

Research by Zangiababdi et al. studied intelligence in beta-thalassemia patients and compared them with their healthy counterparts. They used Wechsler Adult Intelligence Scale (WAIS) test and concluded that the condition

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negatively influenced the patients' abilities in verbal fluency, conceptualization, reasoning and so on [20]. This could also contribute to the patients' dissatisfaction and lower BI scores.

Moreover, overall lower quality of life in thalassemia patients is a topic for discussion, which could impact their BI. A study in Turkey found that a lower quality of life and depressions were more prevalent in these patients, and physicians with adolescent and young patients must be more attentive and caring for the different aspects of these patients' needs [21]. The same results are also reported in India [22]. Given that these findings point towards depression and a lack of confidence, in addition to the self-assessing nature of this study, it can be deduced that patients are more likely to respond more negatively to the questionnaire, indicating a worse BI than what reality might be!

One significant research studied this BI image and self-dilemmas in thalassemia patients with a population pool of 11 adolescents. The mentioned research highlighted issues such as issues with BI, social experiences, academics problems, all of which are in concordance with our results. They also suggested therapeutic attention to these issues, which we agree with! [23]. A randomized control trial from Iran suggested that positive thinking programs positively affected thalassemia major patients' hopes and sleep quality [24].

Before comparing our patients with those with other chronic conditions, we first like to add that, patients with chronic illnesses and the resultant depression are more likely to have eating disorders or other psychological conditions that might exacerbate their perceptive BI [25]. Other chronic illnesses are proven to have a similar psychological impact on the patients' lives. A study by Miaja et al. evaluated changes in the sexuality, BI and fertility in young breast cancer patients and even their partners, finding the negatives associated with these alterations, and suggesting attention and therapeutic management for them [26]. These problems might either persist or emerge even after reconstructive surgery, emphasizing the impact a chronic illness can have on one's life [27]. The same concepts have been studied in men with prostate or laryngeal cancer, finding the same results [28].

Another study by Song et al. in 2014 evaluated the relationship between self-esteem and BI [29]. The present study focused on thalassemia major as a chronic illness in adolescents, the most vulnerable group of patients. Our results, inconsistent with several other studies, represented that the different appearance and all the other limitations caused by the disease could lead to a worse BI in the patients. We think that the complications of the disorder like the lack of puberty, heart complications, diabetes mellitus and so on may also contribute to the formation of an unfavorable BI. In agreement with our finding, some studies mentioned a negative BI as a result of thalassemia [30, 31]. The BI is related to self-esteem and a study by Ganesan et al. in 2020 has indicated that self-esteem is an important factor in causing body image problems particularly in female adolescents [32]. A study by Hasrat Dhanja et al in 2020 mentions that personality traits have a significant relationship with body image [33].

It should be noticed that one's self-image and self-esteem is highly affected by the others' perception. Most of the time, parents and doctors make the situation worse. Parents are often in one of the two ends of a spectrum, negligible or overprotective. Parents who are critical and rejecting cause a feeling of worthlessness or guilt in the patient. On the other side, overprotection makes patients feel weak, vulnerable and fragile. In addition, the medical teams usually do not care about the emotions and psychological demands of patients [31]. All these behaviors and attitudes contribute to the patient's self-image.

Moreover, this study had its limitations. The sample size was small and future studies might benefit more from a larger sample size, increasing the accuracy and the clarity of the study. In addition, it is possible to use other variables such as socioeconomic status and education level to understand their relationship with body image in patients with thalassemia major.

Lastly, it seems quite necessary to benefit from a consultant to train patients and their parents that the illness is not all of their life. They must be trained to adjust to the disorder and tackle its emotional crises.

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Conclusion

An unfavorable BI in adolescents with thalassemia, as a kind of psychiatric disorder, emphasizes the need for emotional and social supports by family, medical staff and peers. As it was found in the present study, as a result of having to deal with thalassemia, in addition to its many physiological complications, patients had to deal with altered appearances and the social stigmas that came with it, particularly in teenagers and adolescents. Therefore, the current study recommends the inclusion of psychological care into thalassemia major patients' treatment regimens, which might improve their quality of life.

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Ethical Code

Consideration ethics: The study is approved by the medical ethics committee of the University of Sistan and Baluchistan in Zahedan (IR.USB.REC.1400.004).

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Conflict of interest

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

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