

The Relationship Between Social Capital and Self-Concept in Adolescents With Thalassemia Major

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Abstract

Background: Thalassemia is among the most common hematological diseases, but it has no definitive cure. The self-concept in adolescents with thalassemia major changes due to changes in their facial form. Among the factors affecting the patient's self-concept is social capital.

Objectives: The study aims to examine the relationship between social capital and self-concept in adolescents with thalassemia major, using a sample of patients admitted to Shafa hospital in Ahvaz, Iran in 2014.

Patients and Methods: This descriptive-analytical study was performed on 146 adolescents (age range, 13-18 years) with thalassemia major who were referred to the hemoglobinopathy ward of Shafa hospital in Ahvaz, Iran to receive blood. The sampling method was a census. Data collection was completed using the Onyx and Bullen social capital questionnaire and Piers Harris's children's self-concept scale. After obtaining the informed consent of the patients' parents, questionnaires were handed to patients in different shifts and answered in the presence of the researcher. To analyze the data, descriptive statistics and analytical statistics (mean, std. deviation, and Pearson correlation) were carried out (CI 95%).

Results: The mean and standard deviation of patients' age was 1.76 ± 15.88 . 53.4% were male. 58.7% of the sample had an average self-concept and 63.2% had average social capital. The mean score of the total sample's self-concept was 11.50 ± 53.36 , which is moderate. The average social capital of all adolescents with thalassemia major was 17.02 ± 87.38 , i.e. in the mid-range. Among the aspects of self-concept, about 70% of participants had an average or poor appearance, attitude, and anxiety. For social trust, more than 90% of participants were average or weak and 75.2% had poor social participation. The dimensions of fame and popularity, appearance, and happiness all had maximal correlation with social capital ($P = 0.0001$). All aspects of social capital except for relations with neighbors and pioneering in social activities had a significant relationship with self-concept ($P < 0.05$). This study shows that a statistically significant relationship exists between social capital and self-concept ($P = 0.001$ and $r = 0.280$).

Conclusions: The results of this study indicate a significant relationship between social capital and self-concept and its dimensions; therefore, self-concept can be increased in adolescent patients by promoting their social capital components.

Keywords: Social Capital, Self-Concept, Adolescent, Beta-Thalassemia

1. Background

Thalassemia is the most common hematological disease that has no definitive cure (1). According to available statistics, each year approximately 60,000 children are born with thalassemia worldwide (2). Iran, with about 20,000 thalassemia patients and 3 million with thalassemia traits, is among the countries located on the thalassemia belt (3). Thalassemia major, the severe form of the disease, has a significant impacts on patients' lives (4, 5). Changes in the face and appearance of these people lead to feelings of loneliness, low self-esteem, and feelings of in-

adequacy, and thus reduce their presence in social activities (6). Physical and mental problems of the disease also affect their social communication (7) and kids and adolescents' involvement in physical and social environments, and change their relationships with peers (8). Increased survival rates due to new treatments (blood transfusions, bone marrow transplantation, and gene therapy), chronic disease treatment, and routine and repetitive treatments may lead to behavioral problems and changes in self-concept in these patients (5).

A study by Georganda on five patients with thalassemia showed that most of them were afraid of not being ac-

cepted by others and being ridiculed because of their looks (9). The work of Verschuere et al. showed that a significant relationship exists between social acceptance and positive self-concept (10). Similarly, Khurana et al. (2006) showed that 68% of children with thalassemia status didn't feel good about their skeletal status and were not satisfied with their mental picture, which also led to low self-concept. Almost all of them referred to their physical appearance as a major cause of their frustration (1). Social acceptance and self-concept improvement is possible through relationships with their peers, family and relatives, being accepted by family and peers (11), and also participation in group games and sports activities (12).

These challenges are more evident during adolescence compared to other stages of development. This period, due to a mismatch of physiological maturity and social maturity, along with psychological instability, can cause many psychological problems such as anxiety, anger, and depression. Teens who have a physical-mobility disability can be more affected by these problems, especially those with chronic diseases that affect key aspects of this period, such as finding friends, identity formation, and social relationships (13). The difficulties of these adolescents include changes in appearance, physical limitations, and dependency on people and treatments like blood transfusions (12), which can lead to reduced quality of life, fewer relationships, and less social capital (13). Social capital denotes all resources existing in the relationships between people and groups, and helps participants to share their knowledge and skills (14). Social capital can be found in the state, neighborhoods, religious centers, schools, gyms, and even shopping centers (15), and it can be a criterion for family and social health, by reducing stress (16).

According to Rotenberg et al. (2004), children and adolescents who have broader social networks (more friendly relations) have higher self-esteem than those who have smaller social networks (17). As a result, emphasizing the rate of social capital in adolescents can be effective in promoting their mental health (18). Social capital is a new concept in nursing; the nurse gives parents the opportunity to examine their child's social context. In general, we can say that social capital is a valuable resource for nurses to improve the effectiveness of high-quality care for patients (19). The nurse, as the most important health care team member who is connected with patients and their families, has a very crucial role in identifying socio-mental health problems in patients and their families (20). Children's nurses occupy a good position to identify the factors that affect the well-being and health of children and families, including social protection mechanisms. Enabling the health of children by supporting their social networks is an important role of these nurses.

2. Objectives

So far, social capital has not been studied in thalassemia patients (19). Therefore, the present study examines the relationship between social capital and self-concept in children with thalassemia major.

3. Materials and Methods

This descriptive-analytical was conducted in 2014, and has ethical approval (ajums.REC.1393.362) from Jundishapur University of Ahvaz. The study population consisted of 150 adolescents with thalassemia aging 13 to 18 years old who were referred to the hemoglobinopathy ward of Shafa hospital to receive blood. Four patients were excluded due to lack of consent. Since all patients referred to the hospital were included through census during the study, there were no available replacements for these four patients, and also no statistical formula. Thus, 146 patients were examined, all of whom have medical records on file. The inclusion criteria were a lack of mental illnesses, being able to read and write, and lack of any impairment or chronic disease other than thalassemia. The study exclusion criteria included an unwillingness to cooperate in completing the questionnaire.

In this study, the hemoglobinopathy ward of Shafa hospital was selected as the study environment to allow access to the appropriate number of patients, and because this hospital is the only center in the area for thalassemia referrals. Shafa hospital is a specialized, educational, referral, and governmental hospital, with a total of 140 beds. The hemoglobinopathy ward has 20 beds and services. The hospital has specialized clinics in adult and pediatric hematology, thalassemia, internal medicine, counseling, genetics, and nutrition. Also, this hospital has admitting wards and started sections.

After explaining the goals of the study to each participant, and explaining that participation was optional and assuring them about confidentiality of the collected data, we asked each participant to read and sign the informed consent form. Also, the participants were given the right to withdraw from the study without charge or penalty. First, the questionnaire gathered information on several demographic variables (age, sex, education level, father's education, mother's education, family size, and number of blood transfusions). The researcher then distributed the Onyx and Bullen questionnaire on social capital and the Piers Harris children's self concept scale among the teenagers in different shifts, and the patients answered both questionnaires in the presence of the researcher. If the patient was unable to answer, the researcher completed the questionnaire, and all samples were studied. So, there was no bias.

The Piers Harris children's self concept scale is used to measure self-concept in children and adolescents age 7 to 18 years old, and includes 80 questions with two options (yes or no) intended to generate a personal report about how children feel about themselves. Scores range between 0 and 80. The scale includes six aspects: 1) behavior; 2) school status and cognitive and mental condition; 3) appearance and physical characteristics; 4) anxiety; 5) popularity; and 6) joy and satisfaction. A score of less than 40 indicates negative self-concept, a score between 40 and 60 shows an average self-concept, and scores higher than 60 indicate a positive self-concept. As the self-concept questionnaire is standard and is widely used in various studies, including Slamani (2003) and Branklin (1981), its validity is approved. The validity reported by Alaei (2010) is 90.12, which that is acceptable. The reliability of the tool is reported by Tailor (1977) to be 0.90, Branklin (1981) places it at 0.92, and Alaei (2010) at 0.89 (12). In this study, the reliability of the questionnaire was obtained by Cronbach's alpha, an acceptable 0.87.

The Onyx-Bullen social capital questionnaire (2000) includes 31 questions in seven dimensions: 1) valuing life; 2) social trust; 3) relationship with neighbors; 4) connection with friends and family; 5) participation in local groups; 6) pioneering in social fields; and 7) capacity to accept differences. The questions use a five-point Likert scale (very low, low, average, high, and very high) which is answered from 1 to 5. The highest score for the questionnaire is 155 and the lowest is 31. A score less than 77.5 shows low social capital, between 77.5 and 116.25 is average, and scores higher than 116.25 show good social capital.

According to Rajabi Guilani, the validity and reliability of the social capital questionnaire has been evaluated by Onyx and Bullen (2000). This study reported a correlation coefficient between 0.52 and 0.87 and a reliability coefficient of 0.84. The reliability of the questionnaire was done in the study by Rajabi et al. in 2013, in which the cognitive aspect had an acceptable reliability of 0.84: structural 0.79 and communication 0.77 (21). According to Bagheri Yazdi, the two-variable correlation coefficient among constituting elements of the social capital questionnaire was between 0.176 and 0.505. Thus, each component of the measure in the questionnaire is a predictor for social capital. The structural validity was 0.809, which is significant. Its reliability was 0.904, which is acceptable (22).

In the present study, the reliability of this questionnaire based on Cronbach's alpha was 0.86. The content validity was determined in the form of a questionnaire to the 10 members of the faculty, who examined the clarity and simplicity of the questions. The determination method used in this study, descriptive statistics (frequency, percent, mean, std.deviation), was used to analyze the dimen-

sions of social capital and self-concept, and the results are shown in the tables as frequency and percentage. A Pearson correlation test was used to examine the relationship between social capital and self-concept and its dimensions. Data was analyzed by SPSS version 22. Thus, $P < 0.05$ was considered as significant.

4. Results

The average and standard deviation of patients' age was 1.76 ± 15.88 . 53.4% were male and 46.6% were female. According to the findings of Table 1, 58.7% had an average self-concept. The average score of self-concept for all samples was in the mid-range: 11.50 ± 53.36 . Among the aspects of self-concept, about 70% of participants had an average or poor appearance and attitude and 73.6% of participants had average or poor anxiety. Levels of happiness and satisfaction in 60.4% of the sample were good.

Table 1. Frequency Distribution and Percentage of Social Capital and its Dimensions^{a,b}

Dimensions	Distribution		
	Weak	Average	Good
Valuing life	17 (11.7)	76 (52.4)	52 (35.9)
Social trust	62 (42.8)	71 (49.0)	12 (8.3)
Relations with neighbors	49 (33.8)	79 (54.5)	17 (11.7)
Relations with friends and family	28 (19.3)	62 (42.8)	55 (37.9)
Participation in local groups	109 (75.2)	31 (21.4)	5 (3.4)
Pioneering in social field	36 (24.8)	77 (53.1)	32 (22.1)
Capacity to accept differences	31 (21.5)	67 (46.5)	46 (31.9)
Social capital	43 (29.9)	91 (63.2)	10 (6.9)

^aValues are expressed as No. (%).

^bMean \pm SD of social capital score obtained 17.02 ± 87.37 .

According to Table 2, 63.2% had average social capital. The mean score of social capital for all samples was 17.02 ± 87.38 , which is in the average range. For social trust, more than 90% of participants were average or weak, and 75.2% had poor social participation. The rate of valuing life in more than 80% of the sample was average or good.

According to the findings in Table 3, all aspects of self-concept have a positive significant relationship with social capital ($P < 0.05$), particularly the dimensions of fame and popularity, appearance, and happiness ($P = 0.0001$). As shown in Table 4, except for relationships with neighbors and pioneering in social fields, all the aspects of self-concept are significant ($P < 0.05$). The results of Table 3 also show that a significant relationship exists between social capital and self-concept ($r = 0.280$ and $P = 0.001$).

Table 2. Frequency Distribution and Percentage of Self-Concept and its Dimensions^{a,b}

Dimensions	Distribution		
	Weak	Average	Good
Behavior	17 (11.8)	67 (46.5)	60 (41.7)
School and rational status	35 (24.5)	44 (30.8)	64 (44.8)
Appearance and attitude	50 (34.7)	62 (43.1)	32 (22.2)
Anxiety	54 (37.5)	52 (36.1)	38 (26.4)
Popularity and fame	29 (20.1)	63 (43.8)	52 (36.1)
Happiness and satisfaction	31 (21.5)	26 (18.1)	87 (60.4)
Self-concept	21 (14.7)	84 (58.7)	38 (26.6)

^aValues are expressed as No. (%).^bMean \pm SD of self-concept score obtained 11.50 ± 53.36 .**Table 3.** Correlation Between Self-Concept and Social Capital in Adolescents

Variables	Correlation Coefficient	Significance Level
Behavior	0.167	0.047
School and rational status	0.197	0.019
Appearance and attitude	0.302	0.0001
Anxiety	0.208	0.013
Fame and popularity	0.392	0.0001
Happiness and satisfaction	0.298	0.0001

Table 4. Correlation Between Self-Concept and Social Capital and its Dimensions

Variables	Correlation Coefficient	Significance Level
Social capital	0.280	0.001
Valuing life	0.177	0.034
Social trust	0.209	0.012
Relationship with neighbors	0.117	0.164
Relationship with friends and family	0.216	0.010
Participation in local groups	0.221	0.008
Pioneering in the social field	0.155	0.065
Capacity to accept differences	0.170	0.044

5. Discussion

In addition to controlling symptoms in patients with thalassemia, improving patient self-concept is important. Therefore, this study aimed to examine the relationship be-

tween social capital and self-concept in adolescents with major thalassemia. In the present study, the mean score of self-concept for all samples was 11.50 ± 53.36 , in the mid-range. The mean score of social capital was 17.02 ± 87.38 , in the mid-range. In a study by Borimnejad et al. (2014), conducted in Golestan province, the mean scores of self-concept in children and adolescents with thalassemia major was in the low range, which is inconsistent with the present study. The reason for this can be socio-cultural differences, particularly economic and literacy differences. On the other hand, unlike the present study, the Borimnejad et al. study included children 7 to 11 years (41.9%), an age group with more limited defense mechanisms than adolescents (12).

The results also showed that a significant relationship exists between social capital and self-concept ($r = 0.280$ and $P = 0.001$). This did not match the Khorasani et al. study. In the study by Khorasani and Asgharpour Masooleh, conducted in 2005 on the students of the University of Mashhad, self-concept had a negative impact on the social capital rate of individuals in neighborhoods ($r = -0.179$). The reason for this inconsistency may be a different study population, culture, security in neighborhoods, sample size, and different geographical location (23). Thompson and Kuperminc (2013), in their study on girls aged 9 to 15 in Georgia, found that increasing social capital also increases self-concept, which is consistent with the present study (24). Demaray et al. (2007), in their study on American students, concluded that a significant relationship exists between social support and self-concept. Adolescents with higher levels of social support from close friends, parents, classmates, and teachers have higher self-concept. This is consistent with the present study (25).

According to the study by Wahl et al. a statistically significant negative relationship exists between social support and the self-concept of students ($r = -0.294$ and $P = 0.005$). When someone has good social support, this will support him or her in the face of difficulties and problems, and also social support will generate acceptance, self-acceptance, self-confidence and self-esteem. In the study by Wahl et al. a significant correlation was observed between social capital and self-esteem, which is consistent with the present study (26). In this study, a significant relationship exists between dimensions of social capital and self-concept, except for relation with neighbors and pioneering in social fields. In the study by Wahl et al. social capital factors ($r = 0.20$, $P = 0.001$) had a positive relation with self-esteem (26). The study by Ashlee and Weining (2012) showed that a significant difference ($r = 0.463$ and $P < 0.001$) was observed between trust and self-esteem. To create a successful social connection, confidence and self-esteem are important factors, and social performances are

effective on people's mental health. That finding is consistent with this study (27). In the present study, social capital is positively and significantly associated with all aspects of self-concept, and among all aspects of self-concept, popularity and fame, appearance, and happiness were most correlated with social capital (0.0001).

Consistently with the present findings, the results of the study by Khoshfar et al. (2014) on youth in Babolsar showed that a direct correlation exists between variables of social capital and youth joy ($r = 0.413$ and $P = 0.0001$). Also, happiness increases with more the social interaction and social trust. So it can be said that social relationships can be a key to joy and happiness (28). Also, Kiamarsi and Momeni (2013) findings on female students in Ardabil showed that a significant relationship exists between social capital and happiness ($P < 0.001$), and that increasing the level of social capital and happiness increases academic achievement ($P < 0.05$). Accordingly, happiness leads to motivation, dynamism and efforts to deal with social activities in life (29). Qaffari and Khani showed that a direct correlation exists between social capital and academic performance by students ($r = 0.314$ and $P = 0.001$). This is consistent with the present study (30). In a study by Nerri and Ville (2008) on students studying in Australia, no significant relationship was obtained between social capital and academic performance, which is not consistent with this study. The reason for this can be cultural diversity, losing support from friends and family, housing instability, lower levels of happiness, and the ability of people to cope with problems (31).

The results of this study, which indicate a significant relationship between self-concept and its dimensions with social capital, highlight the possibility of increasing the self-concept of adolescents by promoting their levels of social capital. Some limitations of the study include the accuracy and honesty of the participants in responding to the questionnaire, and the emotional status of the participants while completing the questionnaire. Environmental factors may also affect the focus of the participants, while individual, educational, and cultural differences influence their perceptions of the questions. Finally, a weakness of the study was the small sample size, despite the researcher's attempts to attract the maximum number of eligible participants through a census. Patients in this study were limited to Ahvaz, and therefore the results are not applicable to all patients in the country. Despite these limitations, this study is the first to examine social capital in thalassemia patients, and its application of social capital to the design of nursing care makes a worthwhile and novel contribution.

5.1. Conclusions

These findings suggest that increasing social capital leads to an increase in adolescents' self-concept. Thus, their self-concept on one hand and their mental health on the other hand can be improved by increasing their social capital components, particularly by increasing their participation in groups. In particular, group membership in voluntary associations, participation in sports, and support from nurses and families can enhance adolescents' social networks. As a result, communication opportunities create and strengthen social and emotional support to improve adolescents' physical and mental health, as well as their self-concept. The results of this study can be a step towards the creation of new ideas or extension of the study in future research.

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Footnotes

Authors' Contribution: Houshang Alijani Renani, Bahman Dashtbozorgi: confirmation and validation of the research process; Abdolreza Navah: conception and design; Maryam Papi, Seyed Mahmoud Latifi: data collection, statistical analysis, and interpretation.

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