

# Effect of Hemoglobinopathies on Adolescent's Behaviour at Heredity Blood Diseases Center

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(Submitted: 22 July 2023 – Revised version received: 03 August 2023 – Accepted: 04 September 2023 – Published Online: 29 October 2023)

## Abstract

**Objectives:** The objectives of the present study were to determine the effect of hemoglobinopathies disease on adolescent's behavior and to find the relationship between adolescent's socio-demographic characteristics and the effect of Hemoglobinopathies on Adolescent's Behavior.

**Methods:** Adolescents male and female with (beta thalassemia and sickle cell anemia) who were between the ages of 12 and 20 were the participants of a descriptive study. The research began on June 17, 2022, and lasted until November 15, 2022 to determine the effect of hemoglobinopathies disease on adolescent's behavior. A non-probability purposive sample of (105) adolescents was chosen at the Heredity Blood Diseases Center in Ibn Al Balady for children and maternity. The information gathered between the 15th of July and the 15th of August 2022 using a built-in questionnaire and a direct interview method.

**Results:** The findings of this study show that hemoglobinopathies disease have a moderate to low effect on adolescents' behavior, with 53.3% of them are showing moderate and 41.9% are showing low.

**Conclusion:** The study conclusion that the behaviour was affected at moderate level. The results recommend offering adolescents with hemoglobinopathies an education program to enable self-management and provide them enough knowledge of the disease to avoid complications and make life plans.

**Keywords:** Effect, hemoglobinopathies, adolescents

## Introduction

Two common hemoglobinopathies globally are beta thalassemia major and sickle cell disease. However, they don't happen very often in the US, where about 101,000 people are affected.<sup>1</sup> Hemoglobinopathies affect teenagers who have suffered from the condition since childhood and require a biopsychosocial strategy. The development of individualized objectives throughout the patient's life, such as illness control, overcoming particular obstacles, and obtaining maximum empowerment, can help them considerably in reaching the best quality of life and behaviors. This is especially crucial during prepuberty and adolescence, which are both viewed from a clinical-biological standpoint as high-risk phases.<sup>2</sup>

Chronic disease causes tremendous stress, deprivation, and severe limitations for children and adolescents who have it. Stress perception can interfere with brain activity, which can cause emotional and behavioral problems.<sup>3</sup> Hemoglobinopathies are a set of diseases in which the normal adult Hgb (HbA) is partially or entirely replaced by aberrant sickle Hgb. Sickle cell anemia (SCA) is one of these diseases. Valine rather of glutamic acid is present at position 6 of the beta chains of the hemoglobin molecule due to a single base alteration in the DNA.<sup>4</sup>

The most prevalent hereditary blood disease, beta thalassemia, affects millions of individuals globally, including in Iraq. Thalassemia patients must need blood transfusions often, which can result in a number of problems.<sup>5</sup> A single inherited autosomal recessive gene is responsible for thalassemia. Hematological conditions brought on by faulty hemoglobin creation of a single or many hemoglobin chains Causes of hemolytic anemia.<sup>6</sup>

Adolescence is a period of maturation that involves significant changes in behavior, especially with regard to risks

and trials.<sup>7</sup> Adolescents who have a chronic illness are more prone than their classmates to reflect risks.<sup>8</sup> Sickle cell disease and thalassemia are serious public health issues in Iraq and other Middle Eastern nations. These hemoglobinopathies are brought on by aberrant chains being produced or by a decrease in the synthesis of globin chains (e.g. sickle cell disorders). With an average carrier prevalence of 4% and around 15,000 people with thalassemia major or intermediate, thalassemia is fairly evenly distributed throughout Iraq. While carrier rates for sickle cell disorders range from 0% to 16.0%, they are less evenly distributed and tend to concentrate in the north and south of the country.<sup>9</sup>

## Methodology and Materials

Male and female adolescents with sickle cell anemia and beta thalassemia who were between the ages of 12 and 20 years were the respondents of a descriptive study. The study took place between June 17, 2022, and November 15, 2022. In order to determine the effect of hemoglobinopathies diseases on adolescents' behavior. The current study was carried out at the Heredity Blood Diseases Center in Ibn Al Balady for Children and Maternity in Baghdad City. Researcher used a non-probability purposive sample of (105) adolescents' patients who have been given the thalassemia and SCA diagnoses were chosen based on a variety of criteria. The study instrument consists of two part. The first part includes data concerning the respondents' general characteristics: gender, age of adolescent, residency, level of education, and Family income. The second part: It consists of (47) items related to adolescent's behavior. Using data from 7 adolescents who were chosen at random for the pilot study, the Alpha Correlation Coefficient (Cronbach's Alpha) was computed to assess the instrument's

internal consistency. The questionnaire exhibited a sufficient level of internal consistency and equivalent measurability based on the reliability result ( $r = 0.79$ ), which was statistically satisfactory. The information gathered between the 15th of July and the 15th of September 2022 using a built-in questionnaire and a direct interview method. Data analysis for this study was carried out using SPSS version 20. The data were analyzed using descriptive and inferential statistical techniques, including the Pearson correlation. The reliability of the questionnaire was evaluated using the correlational coefficient, and a level of statistical significance of 0.05 was chosen.

## Results

The study reveals that the majority of adolescents (60%) are male, with the 12–14 age group accounting for 42.9% of the total. The majority of adolescents (85.7%) live in urban areas. According to the level of education for adolescents, 52.4% of them have graduated from Primary School. Around 38.1% of the monthly income of the families of adolescents is less than 300.000 ID (Table 1).

Table 2 shows that Hemoglobinopathies diseases have effect within moderate level on adolescents' behavior in which 53.3% of them are showing moderate and 41.9% are showing low.

Table 3 indicates that there is no significant correlation between adolescents' behavior with their sociodemographic characteristics of gender, age, residence, education, and family income.

Table 1. Distribution of sample according to their socio-demographic characteristics

No.	Characteristics	F	%
1	<b>Gender</b>		
	Male	63	60.0
	Female	42	40.0
2	<b>Age</b>		
	12–14 years	45	42.9
	15–17 years	33	31.4
	18–20 years	27	25.7
3	<b>Residency</b>		
	Rural	15	14.3
	Urban	90	85.7
4	<b>Level of education</b>		
	Don't read & write	5	4.8
	Read & write	10	9.5
	Primary school graduated	55	52.4
	Intermediate and more	35	33.3
5	<b>Family income/monthly</b>		
	Less than 300.000 ID	40	38.1
	From 300.000–600.000 ID	34	32.4
	From 601.000–900.000 ID	21	20.0
	More than 900.000 ID	10	9.5

No: number; F: frequency; %: percentage.

## Discussion

Throughout the present study indicating that more than half of the study sample were males, it has been mentioned that males are more affected than females. These findings are backed up by a study conducted by (Breakey, et al., 2018),<sup>10</sup> which found that all of his study sample were males.

In regard to the age groups, the findings are shown in Table 1 that the dominant age group of the study sample is within (12–14) years old of age group, this finding disagree with (Mousavi, 2019)<sup>11</sup> study who reported that the majority of the study sample were within age groups (8–12 years).

The majority of the participants in this study live in urban areas. This result agrees with (Mousavi, 2019)<sup>11</sup> who report that more than half sample live in urban areas. The adolescent education level of the present study revealed that more than half of the sample are Primary School graduated. This result disagrees with (Dsouza, 2020)<sup>12</sup> study who report that majority of the study sample was Primary school.

According to the current results, the majority of the sample comes from less than 300.000 ID in terms of family socioeconomic status. This statistic is consistent with the findings of (Shareef & Obaid, 2015),<sup>13</sup> who state that more than half have less than 300.000 ID, the same percentage have between 300.000 and 600.000 ID, a fifth have between 601.00 and 900.000 ID, and more than a tenth have more than 900.000 ID. From the researcher point of view, the majority of adolescents reside in low and middle-income families and explain why only poor families are more likely to bring their children to general hospitals. They may also indicate that wealthy families have the resources to pay for premarital and prenatal screening tests when they are aware of them.

The current study indicates that Hemoglobinopathies disease has moderate to low effect on adolescents' behavior. These findings are backed up by a study conducted by (Badr & Hasan, 2022)<sup>14</sup> which found that (49%) of Hemoglobinopathies adolescents were have poor health behavior. From the researcher's point of view, the reason for this could be that adolescents suffer from distress from both the illness itself and the need for iron chelation, also frequently display maladaptive coping strategies. Table 3 indicates that there is no significant correlation between adolescents' behaviour with their sociodemographic characteristics of gender, age, residence, education, and family socioeconomic status. This finding in the same line with (Badr & Hasan, 2022)<sup>14</sup> which found that there were no significant differences in health behaviour with regards hemoglobinopathies adolescents age ( $P > 0.05$ ). From the researcher's point of view, the reason for this could be that have been because the studied children got used to the presence of the chronic disease while their ages advanced. Also,

Table 2. Determine the total effects of hemoglobinopathies disease on adolescents' behavior

Levels	F	%	M.S	SD
Low (0–47)	44	41.9		
Moderate (48–94)	56	53.3	50.11	18.333
High (95–141)	5	4.8		
Total	105	100		

F: frequency; %: percentage; M.S: mean of score; SD: standard deviation.

Table 3. **The statistical correlation between adolescents sociodemographic characteristics of and their behavior**

Behavior Characteristics	Pearson correlation	P-value	Sig.
Gender	0.236	0.172	N.S
Age	0.206	0.234	N.S
Residence	0.021	0.904	N.S
Level of education	0.063	0.721	N.S
Family income	0.005	0.976	N.S

P: probability  $\leq$  0.05 level; N.S: not significant; S: significant.

this result agrees with (Von Hohendorff, 2013)<sup>15</sup> study who reported that there are no significant differences were found in relation to gender.

Considering age, residence, level of education, and family income according to results there is no significant association with Adolescents' Behaviors. These finding disagrees with (Basu, 2015)<sup>16</sup> who stated that patients with thalassemia was significant relationship with level of knowledge and sociodemographic variables such as age, residence and level of education. According to (Hosokawa, 2018),<sup>17</sup> lower family income, maternal education level, and paternal education level are predictive of all three domains of behavioral disorders (internalized problems, externalized problems, and total behavioral problems).

## Conclusion

More than half of adolescents with Hemoglobinopathies have moderate effect on health behaviour, and All sociodemographic characteristic have not been influencing on behaviours of adolescent with hemoglobinopathies.

## Recommendation

The study recommended that appropriate education be given to adolescents with sickle cell anemia and thalassemia, as well as to their families and other caregivers, in order to enable self-management, adequate comprehension of the problems connected to the condition, and for life planning. Promotion and facilitation of educational and recreational programs in collaboration with patient groups to provide them the chance to discover new interests and skills and form social connections with others who share their medical condition.

## Acknowledgment

I express gratitude to the adolescents with beta thalassemia and sickle cell anaemia who took part in the study.

## Conflict of Interest

Author certifies that they have no competing interests. ■

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