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Physical wellness among adolescents with hemoglobinopathic disorders

Naba'a Hussein Eidan
Master Student, Pediatric Health Nursing, College of Nursing, University of Babylon
*Corresponding author email: nabahussain70@gmail.com

Nuhad Mohammed Aldoori
Assistant Prof., Pediatric Health Nursing, College of Nursing, University of Babylon
Email: Nuhad64@yahoo.com

***Abstract*---**Background: Hemoglobinopathy is a group of genetic disorders transmitted from parents to their children spread all over the world and is characterized by a decrease or absence of the normal synthesis of hemoglobin, as in thalassemia, or the abnormal structure of hemoglobin as in sickle cell anemia, has an impact on physical and Psychosocial wellness, which leads to increased fears about physical appearance, and interference in the process of gaining independence and healthy relationships with family, friends, and society. Aims: To assess physical wellness among adolescents with hemoglobinopathic disorders. As well as to Identify association between the physical wellness with certain demographic data. Methods: A cross-sectional descriptive study design was used during the period from February 2, 2022 to May 2, 2022. This study was conducted in Babylon Governorate on (150) patients with hemoglobinopathic disorders at Babylon Teaching Hospital for Women and Children; 50% of patients aged 10-19 years were selected. Data were collected using a modified questionnaire and analyzed electronically by using SPSS 26. Results: Less than two-fifths of patients range in age from (10–13) years with mean age (of 14.7), half of them are males and the other half are females. The study shows the overall physical wellness for (57.3%) of the sample was moderate. Some variables were associated with physical wellness, such as the patient's age, educational level of patients and parents, the degree of consanguinity between parents, and hemoglobin level at a p-value < 0.05. Conclusions:. The study concludes that there is a significant impact of hemoglobinopathies disorders on the physical wellness of adolescent patients. It is recommended to activate the roles of pediatric nurses and family caregivers in promoting and encouraging children with hemoglobinopathy disorders to achieve improved performance in their

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daily living activities and independence, Particularly for children with little social support and high severity of sickness to increase their awareness by taking care of them in all aspects that affect and weaken their personalities.

***Keywords*---**hemoglobinopathic disorders, adolescents, physical wellness.

Introduction

Hemoglobinopathies are a type of genetic blood disease that affects the structure, function, or generation of the hemoglobin molecule **[1]**. That are characterized by varying degrees of anemia and a wide range of clinical manifestation. They are most common in the Mediterranean region, Sub-Saharan Africa, the Mideast, Central India, and Southeast Asia, where an estimated 400,000 babies are born with significant hemoglobinopathies each year. Ninety percent of these births take place in de developed or development countries **[2]**. In Iraq, between 6-10% of the population has hemoglobinopathy, of which thalassemia is a major component **[3]**. Hemoglobinopathic disorders were first reported in Iraq in the mid1960s of the previous century [4]. Hemoglobinopathy as umbrella term which include all hereditary hemoglobin disorders, this may be either cause qualitative defect such as sickle cell anemia or causing quantitative defect such as thalassemia **[5]**.

A chronic disease affects all parts of a patient's life, not just the physical, but also the social and emotional, educational, and occupational aspects [6]. physical wellness defines as a consist of recognition the need for physical activities, healthy diet and sleeping as well as prevention illness and injury or managing chronic health problems [7]. Self-management is a collection of tasks that persons with chronic illnesses must implement into their daily routine in order to improve their health [8]. Hemoglobinopathic adolescents confront a unique set of challenges. Due to their sensitivity, factors including stigma, delayed menarche, and delayed physical development may have a detrimental impact on them, leading to a negative self-image and dangerous behavior [9].

Objectives of the study

- Assess physical wellness among adolescents with hemoglobinopathic disorders.
- Identify association between the physical wellness with certain demographic data.

Methodology

Design and Sampling

A quantitative, cross-sectional descriptive design is used for the assessment of the physical wellness among adolescents with hemoglobinopathic disorders in the Babylon province from February 2 to May 2, 2022. The sample of the study was selected Purposively (non-probability), made up of 150 adolescents of both

genders who were chosen from records of patients who had been medically diagnosed with beta thalassemia intermediate or major, sickle cell anemia, and sickle thalassemia.

Data Collection

Collection of data by using a questionnaire was modified to accomplish the goals of the current study after a comprehensive review of the relevant literature. It consists of three sections designed to cover all aspects of the study. The first part is for demographic data for the adolescents and their families, the second part for medical history, and the third part is about physical wellness which includes several items for clothing, transferring, school activities, playing, hygiene, and sleeping.

Data Analysis

The data of the present study was analyzed electronically via the Statistical program (SPSS) version 26. The method used in this program aimed to find out the descriptive and inferential statistics such as frequencies, percentages, chi-square, and correlation by entering data to achieve the objectives of the study.

Results

Table 1
Distribution of the Study Sample by their demographic data (N = 150)

Demographical data		Frequency	Percentage %
Age (Years)	10-13	59	39.3
	14-16	49	32.7
	17-19	42	28.0
	Total	150	100.0
	Mean (SD)	14.7 (2.82)	
Gender	Male	75	50.0
	Female	75	50.0
	Total	150	100.0
Patient order among siblings	1-3	96	64.0
	4-6	48	32.0
	7-9	6	4.0
	Total	150	100.0
Patient Level of education	Unable to read and write	11	7.3
	Primary level	65	43.3
	intermediate level	47	31.3
	Secondary level	27	18.0
	Total	150	100.0

Mother Education	Unable to read and write	17	11.3
	Primary level	88	58.7
	Secondary level	30	20.0
	Diploma or above	15	10.0
	Total	150	100.0
Father Education	Unable to read and write	14	9.3
	Primary level	73	48.7
	Secondary level	35	23.3
	Diploma or above	28	18.7
	Total	150	100.0
Mothers occupation	Employed	19	12.7
	Unemployed	131	87.3
	Total	150	100.0
Fathers occupation	Employed	131	87.3
	Unemployed	19	12.7
	Total	150	100.0
Parent consanguinity	Yes	114	76.0
	No	36	24.0
	Total	150	100.0
Economic state of Family	Enough	51	34.0
	Enough to some extent	71	47.3
	Not enough	28	18.7
	Total	150	100.0
Residence	Urban	69	46.0
	Rural	81	54.0
	Total	150	100.0

Table 2
Distribution of the sample according to their Medical Histories (N =150)

Medical History		Frequency	Percent
Type of illness	Major Thalassemia	121	80.7
	Intermediate thalassemia	19	12.7
	Sickle Beta Thalassemia	7	4.7
	Sickle cell anemia	3	2.0
	Total	150	100.0
Frequency of blood transfusion/ month	One time	66	44.0
	Twice	62	41.3
	Three times & over	22	14.7
	Total	150	100.0

Age at diagnosis	1-3	128	85.3
	4-5	12	8.0
	6-12	10	6.7
	Total	150	100.0
Osteoporosis	Yes	50	33.3
	No	100	66.7
	Total	150	100.0
Splenomegaly	Yes	80	53.3
	No	70	46.7
	Total	150	100.0
Hepatomegaly	Yes	30	20.0
	No	120	80.0
	Total	150	100.0
Hepatitis	Yes	10	6.7
	No	140	93.3
	Total	150	100.0
Diabetes	Yes	8	5.4
	No	142	94.6
	Total	150	100.0
Cardiomegaly	Yes	12	8
	No	138	92.0
	Total	150	100.0
Is there more than one affected child in the family	Yes	98	65.3
	No	52	34.7
	Total	150	100.0
BMI Percentile	Less than 5th percentile	33	22.0
	5th to less than 85th percentile	111	74.0
	85th to less than 95th percentile	5	3.3
	95th and more	1	.7
	Total	150	100.0

Table 3
Distribution of sample's Hemoglobin level (N =150)

Mean	7.76
Std. Deviation	.874
Minimum	5.8
Maximum	10.5

Table 4
Overall level of Physical Wellness among Hemoglobinopathy Adolescents (N =150)

Physical Wellness	Frequency	Percentage%	Mean	SD
Poor	18	12.0	50.58	7.6
Moderate	86	57.3		
Good	46	30.7		
Total	150	100.0		

Table 5
The associations between Physical Wellness and their demographic data

Demographical data	X^2	DF	p-value
Age	18.003**	4	.001
Gender	4.061	2	.131
patient Level of education	45.149**	6	.001
patient order among siblings	4.660	4	.324
Mother Education	32.24**	6	.001
Father Education	13.883*	6	.031
Mothers occupation	2.493	2	.288
Fathers occupation	.396	2	.820
Parent consanguinity	7.611*	2	.022
Economic state of Family	8.300	4	.081
Residents	3.266	2	.195

Discussion

Throughout the data analysis, the study shows that the nature of the study sample is described by demographic characteristics of hemoglobinopathic adolescents. Table (1) indicates that most of the adolescents age group are within 10_13 years old with a mean age is (14.7), and equally divided between males and females. This result go in line with the finding of (Issa et al.,2018) that carried out on 100 thalassemic adolescents aged 10_18 years, the demographic characteristics of this study show a majority age group is 10_14 years with high percentage prevalence [10]. In a mixed-methods study design done by (Kambasu et al.,2019), among 140 patients with SCD their age was 8_17 years in order to assess (Health related quality of life of adolescents with SCD in sub-Saharan Africa: a cross-sectional study) which found that mean age was (14.25) years [11].

In case-control study a group of fifty patient with thalassemia major and fifty normal children within age 5_17 years were included by (Elzaree et al.,2018) about the adaptation functions and psychosocial issues among children with major beta-thalassemia had half of sample was male and other half was female [12]. Furthermore, supportive evidence is a descriptive study done by (Shareef & Obaid, 2017), on 50 patients in order to assess the knowledge of adolescents with

thalassemia major regarding iron chelating therapy also found equally distributed of sample according to gender [13]. In relation to the Patient order among siblings in the current study majority of them are between first and third child, which is supported by (Saeed &Aldoori,2020) that conducted in in the Babylon province, who showed that most of adolescent's order in their families are between first and second child [14].

Regarding to patient level of education in the existing study most of them were primary level. Sustained by (Ishfaq et al.,2018), who carried out a cross sectional study on 200 major thalassemic patients in Pakistan as majority of them was primary level of education [15]. Other study conducted by (Batool et al., 2017), who carried out a cross sectional study design on 91 patients with thalassemia major having age 12_18 years most of them was primary educational level [16]. In case-control survey was conducted in Minia University children's hospital on 64 patients and 64 healthy children aged between 8_18 years were done by (Hakeem et al., 2018) about the Health-related quality of life among children and adolescent patients with transfusion-dependent ßthalassemia in upper Egypt, had majority of patients (48.4%) were primary level of education [17].

Parents' level of education in the present study more than half of them were primary level. These findings agree with the study done by (Baiee et al.,2015), they found that majority of participant parents had a primary education level [18]. Whereas a Quasi-experimental study was conducted by (Hassan & Azzab, 2016) who studied (23) children for studying the impact of health instructions on the quality of life and psychological difficulties among thalassemic children. It shows that the highest percentage (43.5 %) of mothers' education was illiterate, while fathers' education level (43.3%) was secondary or above [19]. These results could indicate to the researcher that there are weaknesses in the procedures that can reduce the incidence of Mediterranean Sea anemia, such as stressing and emphasizing the seriousness in conducting marriage examinations as well as counseling for the parents who are carriers or suffer from this genetic disease were poorly applied.

Finding of the parent's occupation in the current study shows majority for mothers are unemployed and fathers are employed. Supportive evidence is provided by (Saeed &Aldoori,2020), they found that majority mothers of thalassemic participants were unemployed, and majority of fathers were employed [14]. This may be rationalized as due to the culture of the society from which the sample was collected does not accept the job for the women and do not allow them to complete their educations, especially if she has children, and in particular those who are sick and in need of continuous and chronic follow-up. The present study also revealed that more than three quarters were respond yes to parent consanguinity. A study included by (Al-Hakeim et al.,2020), on (1122 patients, aged 5 to 65 years old) who studied the "Hereditary Hematologic Disorders in Najaf Province-Iraq" found the consanguinity rate in their patients' parents (78.24%) [20]. From the perspective of the researchers Marriage between relatives has been identified as a significant role in genetic illnesses, which are prevalent in the Iraqi populations.

Regarding to economic state of family, in the current study less than half were enough to some extent and residency of more than half from rural. This result supported by (Saeed &Aldoori,2020), they found economic state for most of the study sample were enough to some extent and the residence area of most thalassemic study sample was rural [14]. Other study done by (Yengil et al., 2014) which conducted on (88) thalassemic patients and (63) caregivers of patients. It concluded that anxiety, depression, and QoL for sufferers and their caretakers', despite of the most of thalassemic patients from rural [21]. Table (2) shows that more than three-quarters of children had major thalassemia. This result agrees with the finding of a study conducted by (Abd et al., 2020) who studied (601) hemoglobinopathic patients titled (Hemoglobinopathies in Thi-Qar Governorate According to Blood Groups) and found that more than three-quarters of the sample had thalassemia [7]. Another study done by (Al-Hakeim et al.,2020), also found thalassemia major is more prevalent than other types of hemoglobinopathic disorders [20].

From the researcher's point of view, these results could refer to the prevalence of thalassemia in Iraq being more than in other types of hemoglobinopathy disorders, this may be attributed to increasing the rate of consanguinity marriage, or neglect of the importance of marriage screening tests by people who are about to get married, especially those who live in the rural area and who have a lack of culture and healthy child development awareness as well as the effect of hemoglibinopathic disorders on their children personalities and body images. Regarding to frequency of blood transfusion the current study shows more than two third of them were take one blood transfusion/ month. This result supported with the finding of cross-sectional case control study done by (Kumaravel et al.,2017), On 32 thalassemic children from 5 to 15 years and 32 healthy children matched with same age and sex, had Transfusion frequency for majority of thalassemic children once monthly [22].

Regarding to age at diagnosis, in the present research vast majority of sample were (1-3) years. In case-control study done by (Mikael& AlAllawi,2018) was conducted among 100 thalassemic children aged 6-18 years and 100 healthy from same age groups, in titled, (Factors impacting the quality of life for thalassemic children and adolescents in Iraqi Kurdistan) they found age of diagnosis for majority of patients from 1 to 3 years [23]. Researchers opinion that the age of disease diagnosis has been early as possible, and they believe that may be early detection of disease help in controlling strenuous complications. In relation to history of disease, disease complication in the current study about two third were didn't have osteoporosis, more than half were having splenomegaly, more than three quarters were didn't have hepatomegaly, and vast majority of them were didn't have hepatitis, diabetes, and cardiomegaly. More supportive evidence is provided by (Abdulsattar & Hattab,2017), they depict in their study that patients experience many long-term complications such as hepatitis, growth retardation and splenomegaly. This rationalized to patients with thalassemia major maybe has a higher risk for recurrence of complications than other types of hemoglobinopathies [24].

Regarding to more than one affected child in the family the present study shows that majority of hemoglobinopathic patients have sibling affected with disease.

Supportive evidence is provided by (Kumaravel, et al., 2017), who carried out a cross sectional case control study on 32 thalassemic children and (32) controls matched to the age and sex. In the Thalassemia children's group majority of thalassemic patients have a sibling with thalassemia [22]. Concerning to BMI Percentile, current research show less than three quarters were between 5th to less than 85th percentile. This finding agree with result of study done by (Saeed &Aldoori,2020), they found the majority of patients were 5th percentile while the majority of healthy adolescents are normal in weight, height, and BMI [14]. The outcome of the contemporary study consistent with an Indian recent article, the conclusion of this article was that hemoglobinopathies patients are short, have lower rates of growth and BMI, and their puberty spurts are either delayed or missing due to sub-optimal iron chelation therapy, low hemoglobin and high levels of ferritin (Saxena, 2017) [25].

The researcher's point of view is that children with hemoglobinopathies have low growth than normal children in the same age group, this may be due to the negative effect of the disease on growth hormone for the affected children. It can be affected by the educational level of mothers who do not have awareness of the problems resulting from iron deposits, which affects the growth and development of children with genetic blood diseases. However table (3) show that the minimum Hb was 5.8 while the Maximum was 10.5, and the mean of Hb was 7.76. This result borders in line with the finding of the study done by (Elzaree et al.,2018), included in a case-control study on a set of 50 children with thalassemia and 50 healthy children of the same age and sex, they find the mean of Hb was 7.79 [12]. Another study conducted by (Venty et al., 2018), on 64 thalassemic children aged 7_18 years, there finding the mean Hb level was 7.18 [26].

The Study has revealed that all the domains of the physical wellness (physical health related to clothing, transferring, school activities, playing, personal hygiene, and sleeping) It had distribution on three scale levels (always, sometime, and never), according to (table 5) more than half of sample having moderate physical wellness for hemoglobinopathy adolescents. Kshaish & Aziz, (2020), carried out a descriptive study about assessment of daily living activities for (100) thalassemic school age children in Baghdad city, they also find most of children are affected moderately in all domains of daily living activities [27]. A cross-sectional study directed by (Moyen et al., 2021), on 201 patients with SCD aged (6_19 years old) in order to determine the (Psychological Experience for Children with Homozygous SCD in Brazzaville) which found that the impact of disease on the patient's daily life was negative in all cases [28].

The findings of current study table (5) indicated that there is a highly significant association between physical wellness and several demographical "data at $p \leq 0.05$", like (age, patient level of education, mother education, father education, parent consanguinity). Similar result in descriptive cross-sectional study was conducted on 100 adolescents with hemolytic anemia by (Issa etal.,2018), in order to assess "Self-concept in Relation to Hemolytic Inheritance Blood Diseases among Adolescents in Babylon Governorate-Iraq" they found that adolescents age" mother education, and father education are highly significant correlation with low self-concept level among sample [10]. Researchers opinion that older children may have increased their abilities for doing their daily living activities

independently, and the higher education level for both patients and their parents leads to an increase in their cognitive abilities and understanding of the disease and its treatment, which may lead to enhance their physical wellness. At the end of the study, the researcher found that the sample has many obstacles and health problems that can be due to the abnormal condition in the red blood cells, which leads to the shortage of hemoglobin, and in turn will effects their quality of life and will be a burden on their peers and families.

Conclusion

The study reaches the following conclusions based on the interpretation and discussion of the study findings. Most of the hemoglobinopathic adolescents in the study sample are mean ages of 14.7 years, and The majority of study samples and their families had a primary level of education. Hemoglobinopathic disorders had a significant impact on the physical wellness of the patients. The age of children and their educational status, as well as parent educational level, parent consanguinity, and hemoglobin level, had a significant impact on the physical wellness of the study sample.

Recommendations

Pediatric nurses and other health care workers must be attentive to the need of determining physical wellness in children with hemoglobinopathic disorders to modify effective management such as early detection, and complication prevention and specifically focusing on documentations. As well as activate their roles in promoting and encouraging the effected children to achieve improved performance in their daily living activities, psychological wellness, and social relationship, Particularly for children with little social support and high severity of sickness. The most important thing is to include their families in caring for them to increase their awareness of taking care of them in all aspects that affect and weaken their personalities. Also, It is recommended that more research be conducted to assess the physical wellness of different age groups and a larger sample that could include all centers in the country.

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