Functional Impairment and Self-Efficacy among Adolescents with Inherited Blood Disorders

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ABSTRACT

Introduction: Inherited blood diseases are a type of hereditary ailment marked by a decrease in normal hemoglobin synthesis or the complete lack of clothing components

Objective: Is to determine which functional impairment raises adolescent risk for psychopathology during adolescence.

Method: A descriptive cross-sectional study was selected to conduct the study of this research was conducted at the Specialized Center of Thi-Qar for genetic blood diseases in order to obtain accurate and comprehensive data on the sixteen teen adolescents, aged eleven to nineteen, who were registered there for treatment, care, and follow-up. The study's objectives were met through the use of the assessment technique. The research was conducted from April 17, 2023, to June 20, 2024. To get the most accurate data, a non-probability (convenience) sampling strategy is used. Version 26 of the SPSS software was used to electronically analyze the data, which was gathered using a questionnaire.

Results: With a mean score of (14.26), the amount of functional impairment was moderate for all emotional domains. For teenagers with inherited blood disorders, the mean score for self-efficacy was moderate (19.27)

Conclusion: The study concludes that, there are significant difference between functional impairment and Self-Efficacy of adolescents with inherited blood disorders

Keywords: Self-Efficacy, adolescents , functional impairment.

INTRODUCTION

Over the past four decades, there has been an increasing interest among behavioral health service providers, policy makers, researchers, and funders in quantifying the extent of functional impairment in children and adolescents.. Functional impairment, as used in diagnosis, is the degree to which a person's presenting symptoms affect their ability to adapt and operate in a variety of settings, including the home, workplace, school, and social situations with friends, family, and other people. 1.

In the fields of psychiatry and psychology, functioning at work, school, in the community, and with family and friends has been widely used to characterize impairment. Children's functioning is seen as a continuum that ranges from the highest level of competence to incompetence in adjusting to the developmental demands posed by their home and school environments (i.e., getting along with parents and siblings, performing well in school, and relating to peers and community members), as well as their neighborhood 2.

Adolescence is a crucial developmental stage for a positive course of future health and well-being when living with a chronic disease (CD), which is often characterized by great variability in its definition, assessment, prevalence, and impact on the child or adolescent 3.

Adolescents with hereditary blood disorders face social life limitations due to emotions of shame or denial, uncertainty about the disease's prognosis, fear of stigma, or impending death 4.

In fact, congenital blood disorders are associated with a number of psychosocial problems like social rejection, psychological distress, and self-stigma apart from physical impairments; and specially, adolescent group may be at high risk. Thus, such challenges may result in a poor quality of life and higher susceptibility to brain disorders such as anxiety and depression 5.

Children with hereditary blood problems have negative outlooks on life, feel different from their peers, and have low self-esteem, remorse, and extreme anxiety. Research has indicated that thalassemia patients have higher rates of depression, anxiety, and shyness when compared to healthy populations 6.

This study is designed to assess functional impairment and Self-Efficacy among Adolescents with Inherited Blood Disorders.

METHODS

Quantitative study / descriptive design (A convenient non-probability) sample was selected about (156) adolescents with inherited blood disorders has been carried out for the period between 18 October 2022 to 8th April 2024.The study was conducted in Thi-Qar Governorates, it was conducted at The Specialized Thi-Qar center for genetic blood diseases

Study Instrument:

Study instrument constructed for the study after review of the related literature. It consists three parts (Socio-demographic data, The Columbia Impairment Scale (CIS) youth version and psychosocial factors for adolescents where used Psychosocial Scales in the Young

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Lives (SYL).The researcher conducted a pilot study in period 1st July to 15th July 2023 to examine the reliability of the tool used in this study. Data collection was started by using tool which fill out by adolescents. It takes 15-20 minutes to complete answering the questionnaire.

Validity has been determined through a penal of five experts who have e necessary experience that qualify them to exam the content of the questionnaire. In addition, internal consistency was established (Cronbach α = 0.79).

Statistical Analysis:

The data were analyzed through the use of Statistical Package of Social Sciences (SPSS) version (26), with the use of frequency, percent, arithmetic mean, standard deviation, and mean of the score (MS) .

RESULTS

Demographic Data

A total number of 156 adolescents diagnosed with inherited blood disorders were included in the study. The mean age of children was 12 ± 18 years. the researcher discovered that the study sample's demographic data indicated that the average age of adolescents with inherited blood disorders is 14.4 years, most of the samples' ages within the age group of 13-15 years. In terms of gender, The sex of adolescents reveals that 66.7% of them are males and 33.3% are females.

The education level 48.1% of adolescents have graduated from primary school, and 41.6% are literate (can read and write).. They are further divided: 6% of them are literate, or able to read and write, The social status refers that 95.5% of adolescents are unmarried and only 4.5% of them are married. The demographic characteristics of children and adolescent patients presented in Table 1.

Table 1. Demographic characteristics of the sample

List	Characteristics		f	%
1	**Age (year) M±SD= 14.4 ± 2.2**	≤ 12	37	23.7
		13 – 15	69	44.2
		16 – 18	50	32.1
		Total	***156***	***100***
2	**Sex**	Male	104	66.7
		Female	52	33.3
		Total	***156***	***100***
3	**Level of education**	Read and write	56	41.6
		Primary school	75	48.1
		Intermediate school	11	7.1
		Secondary school	5	3.2
		Total	***156***	***100***

Table 2. Overall Assessment of Functional Impairment among Adolescents with Inherited Disorders

Impairment	f	%	M	SD	Ass.
Minimal	4	2.6	14.26	4.215	Moderate functional impairment
Mild	64	41			
Moderate	73	46.8			
Severe	15	9.6			
Total	***156***	***100***			

Table 2. showed that 46. 8 percent of the inherited disorders among adolescents affect a moderate level of functional. which has a mean score of 14. 26 years of age and the numbers had a within-subject standard deviation of 4. 215.

Table 3. Assessment of Self-Efficacy among Adolescents with Inherited Blood Disorders

Self-efficacy	f	%	M	SD	Ass.
Low	49	31.4	19.27	4.359	Moderate
Moderate	80	51.3			
High	27	17.3			
Total	***156***	***100***			

Regarding self-efficacy, the table 3. Showed that the low to moderate level self-efficacy is revealed, that is, 51–75% of participants.

Table 4. Correlation between Functional Impairment and Self-Efficacy among Adolescents with Inherited Blood Disorders

Correlation		Self-efficacy	Self-esteem	Parents' relations	Peers' relations	Functional impairment
Self-efficacy	Pearson Correlation	1	.563**	.358**	.397**	.063
	Sig. (2-tailed)		.000	.000	.000	.435
**. Correlation is significant at the 0.01 level (2-tailed).						
*. Correlation is significant at the 0.05 level (2-tailed).						

This table indicates that there is positive significant relationship among functional impairment and self-esteem.

DISCUSSION

Children and adolescents with genotypic haemoglobin-opathies as SCD, ß-thalassemia, and hemophilia mostly have severe disability that affects their self-esteems. These are diseases that persist throughout a person's life, and their management might be complicated during adolescent development – that is a time of life when adolescents develop skills necessary to fit into societies.

Adolescents with inherited blood disorders often have to manage complex treatment regimens, including regular medications, blood transfusions, and physical therapy. The physical and emotional toll of these treatments can lead to feelings of helplessness and a lack of control over their health, diminishing their self-efficacy. Moreover, the unpredictability of symptoms, such as sudden pain episodes in SCD, can further erode their confidence in managing their condition

According to recent studies, adolescents with inherited blood disorders often face unique challenges related to growth, development, and disease management 7.

According to Lara et al. (2023), adolescents, particularly those in the 13–15 age range, are more vulnerable during the transitional period between childhood and maturity. This presents a problem for adhering to treatment plans or raising health standards 8.

There have been reports of gender differences in the distribution and severity of inherited blood disorders such as thalassemia and hemophilia. According to research, men are typically more impacted than women due to the X-linked pattern of inheritance, which affects prognosis and illness control strategies.

Inherited blood diseases mostly related to sickle cell disease (SCD), Thalassemia is at adolescence level for proper functioning of the

disease leads partial disability. Explorations of lack of understanding or learning loss convergences offer some information concerning the degrees and sorts of these in the current study which indicated as being relatively mild to moderate.

Based on the study; the adolescent Inherited blood disorders pointed out that they can experience some functional limitation as a result, it can be evidence that the inherited blood disorder is changing for the worse and the ability of adolescents with inherited blood disorders to function physically, emotionally, and socially is being restricted. For example, the children living with SCD experience episodes of pain, fatigue, and many hospitalizations, which make them have a kind of limited contact with school and peers. 9.

Adolescents with inherited blood disorders, such as hemophilia or sickle cell disease, often face unique challenges that can impact their self-efficacy. These include frequent medical appointments, pain management, and social stigma. The healthcare environment and the support system play significant roles in shaping these adolescents' self-efficacy 10.

CONCLUSION

Adolescents with inherited blood disorders face considerable challenges that impact their physical, cognitive, emotional, and social functioning. These functional impairments can significantly undermine their self-efficacy, affecting their ability to manage their condition and engage in normal adolescent activities. Addressing these challenges through comprehensive medical care, psychosocial support, and interventions aimed at enhancing self-efficacy is essential to improving the overall quality of life for these adolescents.

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