Study of the Encomic Burdens that Affects the Families of Thalassemia Children in General Center for the Treatment of Thalassemia at Misan City

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ABSTRACT

Introduction: Thalassemia is a blood disturbance occurred down during families (genetic) in which the body produces an abnormal shape hemoglobin. This disorder results in excessive destruction at red blood cells, and there is not effective therapy. Patients require lifelong blood transfusion, usually started within 6 to 12 months of birth of the patient, which on other hand has its own many complications. It is a chronic disease that manifests so early in life that it leads to psychological and social problems for parents.

Objectives,(1)to identify encomic burdens that affects the families of thalassemia Children in general Center for the treatment of Thalassemia at Misan City.(2)to Examine relationships between economic burdens that affects the families of Thalassemia and their perceived socio-demographic related data.

Methodology: In this study was used convenient sampling; 53 Children collected representing to the parents of children thalassemia. a questionnaire is constructed by the researchers for the purpose of the study. It is comprised of two parts: First part of questionnaire :Demographic data. consisted of (12) items, Second part of questionnaire: specific information to sample research. That contains of (26) items. The data collected during period from 10 November 2020 and ended in 20 May 2021.

Results, The results of study show that more of the children in age group to the study sample were within (6-10) years was (30.2%).The study also shows that the majority of participants were male (62.3%). that there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status at (P > 0.05).in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%).

Conclusion, The findings there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status.the results show that more half of them in age group to the study sample were within (6-10) years was ,The findings also revealed The majority of the samples suffer from a low economic level.

Recommendation, The disease is among the hereditary diseases that are transmitted from parents who carry the disease to their children. Therefore, we recommend blood tests before marriage to avoid infecting children and what complications happen to them that lead to their death. The necessity of early diagnosis of the disease for the purpose of using appropriate treatment methods to avoid serious complications in the future, such as removing some organs such as the liver, spleen or even the bone marrow.

Key words: Thalassemia children, Economic burden, Famlies.

INTRODUCTION

Thalassemia is a genetic disorder that occurs in the blood and is passed from parents to children. The outcome of this disorder is excessive destruction of red blood cells and there is no effective treatment yet. Therefore, thalassemia patients need blood transfusions for life on a continuous basis, and normally it begins within 6 to 12 months of the birth of the child, and as it appears on the other hand, its own complications. It is considered a chronic disease that appears very early in life and leads to psychological, social and financial problems for the parents[1].

It is globally reported that Thalassemia is one of the most common inherited genetic disorders in India. Statistics show that approximately 8,000-10,000 children are born with thalassemia every year[2]. Despite this, thalassemia is a serious disease that causes severe anemia, ineffective erythropoiesis, extramedullary hematopoiesis, transfusion-induced iron overload and increased absorption of iron[3]. The definitive treatment for thalassemia is bone marrow transplantation, which is out of reach for many patients in this and other countries[4].

Thalassaemia illness are hereditary disorders of (alpha or beta) globin biosynthesis. Transfusion-dependent thalassemia is easily diagnosed during childhood. It is significantly associated with mortality and morbidity. Chronic blood transfusion with red blood cells improves oxygen delivery and prolongs the life of patients with thalassemia major, but the inevitable side effects of iron overload are usually fatal upon reaching the age of thirty[5].

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Thalassemia syndromes are among the most common and dangerous genetic diseases. They are indigenous to a wide but defined geographic area. However, it is through transport that they spread across previously unaffected areas. Thalassemia is occur via mutations in the α (HBA1/HBA2) and β globin (HBB) genes and is usually inherited in a matrimonial manner. The corresponding proteins make up the adult hemoglobin molecule (HbA) which is a heterodimer of two α- and 2-globin chains.

Scientifically, the mutations that cause thalassemia disease lead to the production of an unstable globin chain, and in turn, lead to an obstruction of red blood cell formation. The severity of the disease is diagnosed by the degree to which the chain is largely unbalanced. In the worst disease, survival follows on regular blood transfusions, which in turn cause excessive iron transfusion and eventually lead to secondary multi-organ damage due to accumulated iron toxicity. It therefore requires a periodic monitoring regimen and vigorous treatment, as for the rest of the syndromes the mildest. Thalassemia itself is considered one of the most important public health issues in many countries, which many health policies fail to address and limit its spread. Although comprehensive health care has led to long-term survival and a good quality of life, poor access to basic facilities and management essentials exponentially increases the cost of treatment and leads to poor outcomes. If these requirements are not recognized by measures (such as the Global Burden of Disease Project), which ranks thalassemia patients very low in terms of disability-adjusted life years (DALYs), And it fails to consider that it ranks highly in age from one to four years. Age group, which makes it an important predictor in under-five mortality. Screening for thalassemia according to criteria that should be accepted as a target disease for newborn screening is not sufficient. However, depending on the screening methodology, severe cases of thalassemia will be detected in most care programs in newborn screening for sickle cell disease. This is very important because: (1) it helps predict affected families to have a sick child in the future and (2) it is an important measure of secondary prevention of disease[6].

Furthermore “Thalassemia is a common disorder worldwide with a predominant incidence in Mediterranean countries and Southeast Asia. Approximately, 240 million people are estimated as carriers for βthalassemia throughout the world while 100,000 children with thalassemia major are born annually”[7].

Children living with β-thalassemia major are need a life-long treatment of regularly blood transfusions and take iron chelation therapy ,which cause major (social and financial burdens) on the patients, families, and health care system. The increase prevalence of thalassemia is mainly appear in the developing countries ranging from the Mediterranean Sea, such as: Turkey, Iran, and India to South East of Asia including (Thailand and southern China)[8].

In fact, the cost of treatment for these patients does not cover the need, as well as any other disease, the cost of treatment only. These additional costs include the cost of a medical consultation, laboratory tests, diagnostic tests, the cost of preventing or treating side effects of treatments, and many other indirect costs. Indirect costs include travel expenses, the cost attributable to lost productivity by patients or their healthcare providers, impaired well-being and all other relevant aspects of patients.

Thalassemia is a chronic state caused by genetic abnormality which impacts a child’s normal physiological status. It challenges every person and as well as their family members at (physical; emotional; cognitive level; and disrupts) their quality of life[9].

If the children diagnosed with thalassemia major illness are not keep they usually die between the age of (1-8) years old. The treatment pattern should be continued for these patients throughout their lives. Accordingly, it was found that the only treatment for a thalassemia major patient is the method of bone marrow transplantation. Hence, the bone marrow transplant is very expensive, costing more than two million rupees. It is necessary and essential to have a completely compatible donor with tissues that match the thalassemia patient exactly. It is most likely and preferable that the donors be from a brother or sister who suffers from thalassemia major. Health care financiers, including governments, social security funds and insurance companies, are struggling to cover the rising costs of medical treatment. Spending on medical treatment is a special target of their interest for several reasons, such as the size of the large drug bill; Easily measure drug costs and prove wasted prescriptions[10].

The recent study's explorations may be effective in controlling, manipulation, managing costs, and providing effective treatments that are distributed in the various health sectors for the care of thalassemia patients. Saving treatment costs for patients with thalassemia major can help in making decisions about regular screening programs.

METHODOLOGY

Descriptive survey approach was used in this study. Convenient sampling was done for this study; (53) patients, samples collected representing to the parents of children thalassemia. The total period of study lasted five months started from 2020/ 11/10 and ended in 2021 / 5/10. The tools used in the current study contains : One part of questionnaire: Demographic information. consisted of (12) items, which include, age, gender, number of family members, ordinal of the child, educational level of mother, educational level of father, occupation status of mother, occupation status of father, economic status, social status of the family, type of family and type of house. Second part of questionnaire: specific information to sample research. That contains of (26) items, which included question regarded related to the parents of children thalassemia and questions about the introduction, causes, signs and symptom , nursing care and treatment of thalassemia. Statistical analyze of data was via means of SPSS Statistics version 24. Researcher used descriptive statistics matter, which include frequency, percentages, mean and Pearson chi-square.

RESULT

Analyze findings of the study sample is a systematically in tables and these match with the aims of the research as follows: Table (1): Distribution of demographic data the parents of children thalassemia. (n= 53 child) No.

No.	Variables	Characteristics	Frequency	Percent
1-	Age (year)	1-5	10	18.9
		6-10	16	30.2
		11-15	15	28.3
		16-20	12	22.6
		Total	53	100.0
2-	Gender	Male	33	62.3
		Female	20	37.7
		Total	53	100.0
3-	Number of family members	1-5	13	24.5
		6-10	37	69.8
		11-15	3	5.7
		Total	30	100.0

4-	Ordinal of the child	1 rank	28	52.8
		2 rank	20	37.7
		3 rank	2	3.8
		4 rank	3	5.7
		Total	30	100.0
5-	Educational level of mother	Do not read or write	16	30.2
		Read and write	2	3.8
		Primary	20	37.7
		Secondary	15	28.3
		Total	30	100.0
6-	Educational level of father	Do not read or write	7	13.2
		Read and write	2	3.8
		Primary	26	49.1
		Secondary	11	20.7
		Institute or college	7	13.2
		Total	53	100.0
7-	Occupation status of mother	Employment	2	3.8
		Unemployment	51	96.2
		Total	53	100.0
8-	Occupation status of father	Employment	30	56.6
		Unemployment	23	43.4
		Total	53	100.0
9-	Economic status	Good	3	5.7
		Moderate	39	73.6
		Poor	11	20.8
		Total	53	100.0
10-	Social status of the family	One of them died	3	5.7
		Death of parents	1	1.9
		Parents are together	49	92.5
		Total	30	100.0
11-	Type of family	Nucleus	41	77.4
		Extended	12	22.6
		Total	30	100.0
12-	Type of house	owned	24	45.3
		rent	21	39.6
		other	8	15.1
		Total	30	100.0

The results of this table show that more of the children in age group to the study sample were within (6-10) years was (30.2%). The above table also shows that the majority of participants were male (62.3%). %). Also, in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%), and most of the children involved in this study are ranked first in the family (52.8%). Also, in regarding to the subjects level of education of mother, the results show that more level of them has primary graduates (37.7%), As well as for the educational level of the father will be among the graduates of the primary (49.1%). In addition, the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%). majority of teachers for occupational status in the study sample were employment (73.3%), while the economic status presented that the majority in the study sample were moderate (73.6). In regarding to the social status shows that the majority of participants were parents are together (92.5%). Also, with regard to the results of this table, most of the children participating in this study are from single families (77.4%). Finally, in the table above, results revealed that the majority of the participants live in a homes owned by them (45.3).

Table (2): Cross-tabulation and Correlation between the effect of economic burden toward parents' children of thalassemia and their occupational status of father. As presented in mentioned table revealed that was high significant association between a parents' economic status toward children of thalasemia and their Occupation status of father at ($P < 0.05$) ,when analyzed by chi-square test.

Occupation status of father		Economic			Total
		Never	some-times	Always	
Employment	F	14	13	3	30
	%	26.4%	24.5%	5.7%	56.6%
Unemployment	F	4	13	6	23
	%	7.6%	24.5%	11.3%	43.4%
Total	F	18	26	9	53
	%	34.0%	49.0%	17.0%	100.0%
χ^2obs.= 14.860 χ^2crit. =9.958 df=4 p value=0.04 P < 0.05					

Table (3): Cross-tabulation and Correlation between the economic burden toward parents' children of thalassemia and their economic status. As presented in mentioned table revealed that there was high statistical significant difference between the effect of economic burden toward parents children of thalassemia and their economic status at ($P > 0.05$).

Economic Status		Economic burden			Total
		Never	sometimes	Always	
Good	F	0	3	0	3
	%	0.0%	5.7%	0.0%	5.7%
Moderate	F	14	21	4	39
	%	26.4%	39.6%	7.5%	73.6%
Poor	F	4	2	5	11
	%	7.5%	3.8%	9.4%	20.8%
Total	F	18	26	9	53
	%	34.0%	49.1%	17.0%	100.0%
χ^2obs.= 11.787 χ^2crit. =9.944 df=4 p value=0.01 P < 0.05					

Table (4): Association between the effect of economic burden toward parents children of thalassemia and their type of housing. as presented in above table, indicates that there was a high significant relationship among the effect of economic burden toward parents children of thalassemia and their type of housing at ($P < 0.05$).

Type of housing		Economic burden			Total
		Never	Sometimes	Always	
Owned	F	3	18	3	24
	%	5.7%	34.0%	5.7%	45.3%
Rent	F	12	5	4	21
	%	22.6%	9.4%	7.5%	39.6%

Other	**F**	**3**	**3**	**2**	**8**
	%	**5.7%**	**5.7%**	**3.8%**	**15.1%**
Total	**F**	**18**	**26**	**9**	**53**
	%	**34.0%**	**49.1%**	**17.0%**	**100.0%**
χ^2obs.= 13.486		**χ^2crit. =9.488**		**df=4**	
p-value=0. 000		**P < 0.05**			

Table (6): Association between the effect of economic burden toward parents children of thalassemia and their type of family. as presented in this table, indicates that there was a significance association between the effect of economic burden toward parents children of thalassemia and their type of family at (P < 0.05) ,when analyzed by chi-square test.

Type of family		**Economic burden**			**Total**
		Never	**Sometimes**	**Always**	
Nucleus	**F**	**17**	**20**	**4**	**41**
	%	**32.1%**	**37.7%**	**7.5%**	**77.4%**
Extended	**F**	**1**	**6**	**5**	**12**
	%	**1.9%**	**11.3%**	**9.4%**	**22.6%**
Total	**F**	**18**	**26**	**9**	**53**
	%	**34.0%**	**49.1%**	**17.0%**	**100.0%**
χ^2obs.= 8.570		**χ^2crit. =5.991**	**df=2**	**P value=0. 01**	
P > 0.05					

DISCUSSION OF THE STUDY

The results of table 1 show that more of the children in age group to the study sample were within (6-10) years was (30.2%). The above table also shows that the majority of participants were male (62.3%). %). Also, in regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) member was (69.8%), this study which presented by[11], illustrates that more of the studied children (26.6%) their age ranged between (>5 – 10) years, the majority (61.7%) of children were males.

Most of the children involved in this study are ranked first in the family (52.8%), and concerning the achievement education, most of parents (49.1%) were father while (37.7%) were mother in the study are primary level. Related to parents' educational qualification, the results of the current study agreed with[12] who stated that more than third of the parents' had primary level education. Also, this study revealed the economic status presented that the majority in the study sample were moderate (73.6)[13].

In addition, the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%), while In regarding to the social status shows that the majority of participants were parents are together (92.5%). Also, with regard to the results of this table, most of the children participating in this study are from single families (77.4%). Finally, in the table above, the outcomes appeared that the majority of sample live at homes owned by them (45.3). this study is agreed with Tafash, Saad Ahmed Younis 2006. Study of the characteristic features of patients with Thalassemia and their relationship to some variables) where the number of males exceeds the number of females and their average age is 8 years[14].

The correlation between the effect of economic burden toward parents' children of thalassemia and their occupational status of father, revealed that there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status, this study agree with Tafesh, Asaad Ahmad Younis, 2006 (Study the characteristic features of children with thalassemia and their relationship to some variables) There are statistically significant differences in personality traits between children with Thalassemia attributable to the economic level of the family. The MSA test in the fifth and eighth questions. As for the outcome of the research, they came as follows: The personal traits intended in this study tend to be somewhat positive, with slight differences in the level of availability of these traits in the same gender on the one hand, and between males and females on the other hand[15].

Association between the effect of economic burden toward parents children of thalassemia and their type of housing, indicates that there was a significant relationship between the effect of economic burden toward parents children of thalassemia and their type of family at (P < 0.05) ,when analyzed by chi-square test.in study of Ammar Sidqi Abdul-Ghani Jayyousi, 2008 (Thalassemia disease and related provisions in Islamic jurisprudence) Where he discussed in his study the psychological and economic burdens that affect me. Families and parents of children with thalassemia. As the effects and problems multiply for them then. There were more than one injured child in the family, and this undoubtedly poses more pressure on the family and makes the matter more difficult as the patient needs a long period of treatment that is not limited to only. Blood transfusion and disposal of excess iron in the body can lead to behavioral and social problems in the patient[16-18].

CONCLUSION AND RECOMMENDATION

Regarding to the present study findings, the researcher concludes the following:

The results of our study show that more of the children in age group to the study sample were within (6-10) years was (30.2%). Also shows that the majority of participants were male (62.3%). In regarding to the subjects number of family members, the results show that more half of them in age group to the study sample were within (6-10) years was (69.8%), and the results shows that most of the children involved in this study are ranked first in the family (52.8%). The subjects level of education of mother, the results show that more level of them has primary graduates (37.7%), The findings revealed that the educational level of the father will be among the graduates of the primary (49.1%). And the occupational status of most of the mothers of the children involved in the study sample was unemployment (96.2%), but for most of them fathers were employed (56.6%). The majority of parents for occupational status in the study sample were employment (73.3%), while the economic status presented that the majority in the study sample were moderate (73.6).

The social status shows that the majority of participants were parents are together (92.5%). The study revealed most of the children participating in this study are from single families (77.4%). The findings demonstrated which the majority of the participants live at the homes owned by them (45.3). In our study the results revealed high significant association between the parents' economic status toward children of thalasemia and their Occupation status of father. The findings in our study revealed The majority of the samples suffer from a low economic level and there was high significant relationship between the effect of economic burden toward parents children of thalassemia and their economic status.

RECOMMENDATIONS

The disease is among the hereditary diseases that are transmitted from parents who carry the disease to their children. Therefore, we recommend blood tests before marriage to avoid infecting children and what complications happen to them that lead to their death. The necessity of early diagnosis of the disease for the purpose of using appropriate treatment methods to avoid serious complications in the future, such as removing some organs such as the liver, spleen or even the bone marrow. Helping patients and their families with complete psychological support does not cause them problems that affect them. If a person is infected with or is a carrier of thalassemia and you can get married and his offspring do not suffer from this disease, God willing, then he must marry a person who is not infected and also does not transmit the disease. The Expanding the study of the disease, especially the related economic burdens for poor families.

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