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RESEARCH ARTICLE

Assessment of Parents' Knowledge about Home Health Care Management to Children with Beta Thalassemia Major

Riyadh Saad Atshan [1], Afifa Radha Aziz [2] *

1. *Lecturer / Al-Furat Al-Awsat Technical University, Medical Technical Institute / Kufa, Department of Nursing Techniques, Iraq;*
2. *Prof. Dr. / University of Baghdad, college of nursing, paediatric Department.*

Corresponding author: Riyadh Saad Atshan
Email: Riyad.atshan.iku@atu.edu.iq

ORCID: 0000-0002-0106-5872

ABSTRACT
Thalassemia is a hereditary condition that affects the formation of globin chains. Beta thalassemia is characterized by either a total loss of manufacture globin (β-thalassemia major) or a partial loss of globin manufacture (β-thalassemia minor). This type of inherited anemias is found in Mediterranean and Southeast Asian communities. Objective: Assessment of parents' knowledge regarding home health care management related to children with β-Thalassemia Major. Methodology: A descriptive study design was carried out at Thalassemia Center in Al-Najaf City during the periods 25 th February 2021 to 15 th March 2022. Non-probability (purposive) sample of (35) parents were selected from thalassemia center (22 mothers and 13 fathers). Results: The finding shows that 77.1% of parents are resident in urban. The monthly income, over than half (54.3%) of parents consider their income to be barely sufficient. The sources of information about disease among parents; (88.6%) of parents are getting information from medical team. The parents are demonstrating poor knowledge level in most domains about home health care management of child with beta thalassemia major. Conclusion: The current study shows that there is a significant inadequacy in the parents' knowledge of the child with beta thalassemia major. Recommendation: Providing educational guidelines, posters, pamphlets and manuals about thalassemia and should be available at each parents in wards and encourage parents to get use from them.

Keywords: Assessment, Knowledge, Thalassemia

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INTRODUCTION

Hemoglobinopathies is an inherited defect in globin synthesis or structure. In homozygotes an abnormal globin chain is inherited from each parent leading to fragile RBCs with diminished lifespan. In heterozygotes the gene is inherited from one parent only (Jamwal, Sharma, & Das, 2020). Chronic red cell transfusions were the only available treatment modality for thalassemia major until about 20 years ago and patients rarely survived beyond the age of 25 (Porter, 2018). There are around (200) distinct mutations that cause globin production to be absent or reduced. The 20 most prevalent aberrant alleles account for 80% of all known thalassemias worldwide; B-thalassemia alleles are found in 3% of the world's population, and 5-10% of the population has B-thalassemia alleles in Southeast Asia has alleles for a-thalassemia(Thompson, 2018). Cooley's anaemia it is otherwise known as beta thalassemia major. Normally one inherits one beta chain gene from each parent. When the genes inherited from both parents are defective Cooley's anaemia results.(ayanan, 2017). Hemoglobin and hematocrit levels are monitored, and packed red blood cells are transfused at regular intervals, are part of the treatment of children who have ß -thalassemia major. Iron levels in the blood are also checked, and iron chelation therapy is administered. The main purpose of nursing care for children with thalassemia is to support the family while also limiting the illness's impact. This covers things like blood transfusions and family education. (Taher A. T., 2021).

METHOD

A Descriptive study design to assess the parents' knowledge about home health care management to children with Beta thalassemia-major. Had been applied during the period 25 th February 2021 to 20 th March 2022. In order to get valid and comprehensive data, the study has been done at Thalassemia Center in Al-Najaf City. This center provides free healthcare to children with thalassemia. Non-probability (purposive) sample of (35) parents were selected from thalassemia center in Al-zahra teaching hospital for maternity and children (22 mothers and 13 fathers). The content validity of the early produced instrument is determined by an expert panel that looks into the questionnaire's clarity, relevancy, and suitability in measuring the notion of interest. The questionnaire design is a preliminary version that was submitted to (16) specialists. The Pearson Correlation Coefficient was utilized to establish the instrument's reliability. Social Science Program (IBM SPSS) version 26.0 used to determine the reliability. The questionnaire's reliability was statistically good, indicating that it had a sufficient level of internal consistency and equivalent measurability.

RESULTS

The residency variable shows in table (1) that 77.1% of parents are resident in urban. The occupational status shows the highest percentage to housewives mothers of children (=54.3%). The number of children in the family refers to four children or more as seen with highest percentage (48.6%). In addition to the monthly income, over than half of parents consider their income to be barely sufficient, as seen (54.3%).

The table (2) shows the sources of information about disease among parents; (88.6%) of parents are getting information from medical team. (2.9 %) of parents are getting information from books and magazine. (42.9 %) are getting information from internet. (5.7%) are getting information from media.

The table (3) displays that parents in the study group showing a poor level of knowledge about home health care of child with thalassemia (85.7%), fair knowledge (11.1%), and good level of knowledge (3.2%).

The table (4) indicates that among parents, is significant relationship with the sub-domain of parents' knowledge about definition, causes, and types of disease with regard to their residency at (p-value= .047.)

The table (4) indicates the parents had a high significant relationship between their knowledge and its occupational status, at (p-value=.007) particularly the domains of "definition, causes, and types of disease" (p-value= .028) and "treatment prevention" (p-value=.047).

The table(5) demonstrates a significant relation among sub-domain of parents' knowledge about "treatment and prevention" with regard to their monthly income at (p-value= .011).

The table (6) demonstrates a high significant relation among parents' knowledge with regard to sources of information at p-value= .009 as seen among sub-domain of "Definition, causes," Treatment and prevention ", Blood transfusion, ".

Table (1): Distribution of the Sample According to their Socio-demographic Characteristics

No.	Characteristics		f	%
1	Residency	Urban	27	77.1
		Rural	8	22.9
		Total	*35*	*100*
2	Occupation	Employee	5	14.3
		Free work	6	17.1
		Housewife	19	54.3
		Retired	2	5.7
		Unemployed	3	8.6
		Total	*35*	*100*
3	Number of children in family	1	1	2.9
		2	8	22.9
		3	9	25.7
		4+	17	48.6
		Total	*35*	*100*
4	Monthly income	Sufficient	4	11.4
		Barely sufficient	19	54.3
		Insufficient	12	34.3
		Total	*35*	*100*

No.	Sources		f	%
1	Medical team	Yes	31	88.6
		No	4	11.4
		Total	*35*	*100*
2	Books & magazine	Yes	1	2.9
		No	34	97.1
		Total	*35*	*100*
3	Internet	Yes	15	42.9
		No	20	57.1
		Total	*35*	*100*
4	Media	Yes	2	5.7
		No	33	94.3
		Total	*35*	*100*

No: Number, f: Frequency, %: Percentage, M: Mean, SD: Standard deviation

Table (2): Overall Assessment of Parents' Knowledge about Home Health Care Management to Children with Beta-Thalassemia Major

No: Number, f: Frequency, %: Percentage

Table (3): Overall Assessment of Parents' Knowledge about Home Health Care Management to Children with Beta-Thalassemia Major

Levels of Knowledge	Study Group (N= 35)			
	Pre-test			
	f	%	M	S.D
Poor	30	85.7	53.71	13.02
Fair	4	11.1		
Good	1	3.2		
Total	*35*	*100*		

f: Frequency, %: Percentage, M: Mean of total score, SD Standard deviation of total score

Poor= 46 – 76, Fair= 77 – 107, Good= 108 – 138

Table (4): Independent T-test for Parents' Knowledge with regard to their Residency

Knowledge / Residency		(N=35)					
		M	SD	t	df	Sig.	p≤0.05
General	Urban	10.33	2.038	.242	33	.810	N.S
	Rural	10.13	2.475				
Definition, causes, and types of disease	Urban	17.15	2.349	2.060	33	.047	S
	Rural	15.25	2.053				
Signs & symptoms and methods of diagnosis	Urban	10.74	1.655	1.248	33	.221	N.S
	Rural	9.88	1.959				
Treatment and prevention	Urban	19.93	3.720	.036	33	.971	N.S
	Rural	19.88	2.588				
Blood transfusion	Urban	13.56	1.888	.532	33	.598	N.S
	Rural	13.13	2.416				
	Rural	8.25	2.252				
Total	Urban	94.89	11.830	1.128	33	.268	N.S
	Rural	89.75	9.192				

M: Mean, SD: Standard deviation, t: t-test, df: Degree of freedom, Sig: Significance, p: Probability value, N.S: Not significant

Table (4): Analysis of variance for Parents' Knowledge with regard to their Occupation

Occupation / Knowledge	Sources	(N=35)				
		Sum of squares	df	Mean Square	F	Sig.
General	Between Groups	33.250	4	8.312	2.115	.104
	Within Groups	117.893	30	3.930		
	Total	151.143	34			
Definition, causes, and types of disease	Between Groups	57.838	4	14.459	3.159	.028
	Within Groups	137.305	30	4.577		
	Total	195.143	34			
Signs & symptoms and methods of diagnosis	Between Groups	22.098	4	5.524	2.057	.112
	Within Groups	80.588	30	2.686		
	Total	102.686	34			
Treatment and prevention	Between Groups	108.785	4	27.196	2.738	.047
	Within Groups	297.958	30	9.932		
	Total	406.743	34			
Blood transfusion	Between Groups	31.687	4	7.922	2.307	.081
	Within Groups	102.998	30	3.433		
	Total	134.686	34			
Total	Between Groups	1620.259	4	405.065	4.382	.007
	Within Groups	2772.884	30	92.429		
	Total	4393.143	34			

df: Degree of freedom, F: F-Statistic, P: Probability value

Table (5): Analysis of Variance for Parents' Knowledge with regard to their Monthly Income

Income / Knowledge	Sources	(N=35)				
		Sum of squares	df	Mean Square	F	Sig.
General	Between Groups	2.845	2	1.422	.307	.738
	Within Groups	148.298	32	4.634		
	Total	151.143	34			
Definition, causes, and types of disease	Between Groups	1.700	2	.850	.141	.869
	Within Groups	193.443	32	6.045		
	Total	195.143	34			
Signs & symptoms and methods of diagnosis	Between Groups	14.528	2	7.264	2.637	.087
	Within Groups	88.158	32	2.755		
	Total	102.686	34			
Treatment and prevention	Between Groups	99.638	2	49.819	5.191	.011
	Within Groups	307.105	32	9.597		
	Total	406.743	34			
Blood transfusion	Between Groups	1.580	2	.790	.190	.828
	Within Groups	133.105	32	4.160		
	Total	134.686	34			
Total	Between Groups	178.617	2	89.308	.678	.515
	Within Groups	4214.526	32	131.704		
	Total	4393.143	34			

df: Degree of freedom, F: F-Statistic, P: Probability value

Table (6): Analysis of variance for Parents' Knowledge with regard to Sources of Information

Sources / Knowledge	Sources	(N=35)				
		Sum of squares	df	Mean Square	F	Sig.
General	Between Groups	8.860	1	8.860	2.055	.161
	Within Groups	142.283	33	4.312		
	Total	151.143	34			
Definition, causes, and types of disease	Between Groups	27.260	1	27.260	5.358	.027
	Within Groups	167.883	33	5.087		
	Total	195.143	34			
Signs & symptoms and methods of diagnosis	Between Groups	.952	1	.952	.309	.582
	Within Groups	101.733	33	3.083		
	Total	102.686	34			
Treatment and prevention	Between Groups	68.810	1	68.810	6.719	.014
	Within Groups	337.933	33	10.240		
	Total	406.743	34			
Blood transfusion	Between Groups	17.202	1	17.202	4.832	.035
	Within Groups	117.483	33	3.560		
	Total	134.686	34			
Total	Between Groups	828.810	1	828.810	7.673	.009
	Within Groups	3564.333	33	108.010		
	Total	4393.143	34			

df: Degree of freedom, F: F-Statistic, P: Probability value

DISCUSSION

The current study shows the highest percentage to housewives mothers of children (54.3%). These findings agree with a study of (Abo Jeesh, Yousif, & Al-Haboub, 2018), who indicated that most the parents occupations (66.4%) were housewives mothers.

The family's number of children refers to four children as seen with highest percentage (48.6%). These findings are consistent with those of a study of (Salih, 2014) who indicated that (60%) of his study has four or more children in the family.

The parents shows poor knowledge level in most items, This result is consistent with (Moghadam, et al., 2016) who discover that the findings suggest that the experimental group had pre-test scores (63.4%) of subjects lacked knowledge.

there is statistical significant relationship between the sub-domain of parents' knowledge with regard to their residency The findings of the study agree with those of a previous study (Habib, et al., 2018) who Showing higher significantly associated between Parents' knowledge, attitude, and practice with their residency.

there is statistical significant relationship between knowledge of parents' with regard to their occupational status this result disagrees with (Hanon, 2015) That revealed working caregivers had significantly higher odds of having satisfactory knowledge regarding the disease.

there is statistical significant relationship between parents' knowledge and regard to sources of information as seen among most sub-domains, The study findings agree with study done by (Shaker, 2019) That revealed there is a clear association between parental knowledge, attitude, and practice with the Sources of information about thalassemia.

CONCLUSIONS

The parents in the study group are demonstrating poor of knowledge about home health care of child with thalassemia.

ETHICAL CONSIDERATIONS COMPLIANCE WITH ETHICAL GUIDELINES

Ethical approvals for the study were getting from the Scientific Research Ethics Committee at the College of Nursing and Ethics committee of the Al-Najaf health directorate and permission to conduct research to ensure their approval and collaboration for data collection of the parent's. All study participants are from Al najaf city sign the consent form.

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AUTHOR'S CONTRIBUTIONS

Study concept; Writing the original draft;Data collection; Data analysis and Reviewing the final edition by all authors

DISCLOSURE STATEMENT:

The authors report no conflict of interest.

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