Original Article

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Knowledge regarding Thalassemia among Parents of Children with Thalassemia at a Tertiary Hospital, Province 2

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ABSTRACT

Introduction: Thalassemia is a genetic blood disorder requiring lifelong treatment and care. Parents play a great role in the care of these children. Thus, this descriptive, cross-sectional study was conducted to assess the knowledge of Thalassemia among the parents with children of Thalassemia.

Methods: Purposive sampling technique was used to collect data from 40 parents of children with Thalassemia attending a Tertiary Hospital, during April to May 2022 and meeting the eligibility criteria. Data collection was done through interview using self-constructed, semi structured questionnaire with the help of research assistant after ethical approval from IRC, TU IOM. The findings were analyzed using Statistical Package for Social Science version-16. Descriptive statistics and inferential statistics (Chi-square) use to analyse the data.

Results: Findings revealed that 45.0% of the children were more than 5 years of age, 60.0% of the children were male and 77.5% of the children were diagnosed at the age of less than one year. 75.0% of the parents of children with thalassemia had inadequate and 25.0% of the respondents had adequate knowledge regarding Thalassemia. There was no association between age of respondent, relation with child, religion, residence, family type, education, occupation and income with level of knowledge.

Conclusions: Based on the findings it is concluded that majority of the respondents had inadequate knowledge regarding Thalassemia, especially in the areas like causes of thalassemia, carrier status, regular follow up investigations, treatment modalities and prevention.

Keywords: Knowledge, parents, thalassemia, thalassemic children

INTRODUCTION

Beta thalassemia is the most prevalent form of congenital hemolytic anaemia.[1] Approximately, 240 million (1.5%) of world population are estimated carriers of beta thalassemia.[2] In the year 2006, World Health Organization (WHO) pronounced thalassemia as a major public health concern [3]. In a study in India, 21.9% of people suffered from abnormal haemoglobinopathies.[4] Among 4018 cases, in Nepal 36.5% of them had haemoglobinopathy related disorder.[5] Thalassemia is most common in low terai, mid hill region and in all ethnicity.[6] Beta Thalassemia is a lifelong disease.[7] In Nepal many children die every year from β-thalassemia without being proper diagnosed, undiagnosed or misdiagnosed and also among diagnosed many die due to no treatment or inadequate treatment[6]. It not only affects child's functioning but also affects the family emotionally and financially.[8] Its curative and maintenance cost is high, so prevention by creating awareness is the only best cost effective way to minimize its burden.[9] Aware parents will provide quality care, follow treatment and prevent birth of another thalassemic child and also can raise the community awareness.[2,10] So researcher is

interested to assess the knowledge of Thalassemia among parents of thalassemic children.

METHODS

Descriptive cross-sectional research was conducted in Narayani Hospital, Province 2, Nepal to find out knowledge regarding thalassemia among the parents of children with Thalassemia. Nonprobability purposive sampling technique was used to select the samples. There were around 50 children getting regular treatment of thalassemia in Narayani hospital as per the record of Paediatric ward Narayani Hospital. Among them, 44 children received blood transfusion in 16th July to 16th August 2021), 41 children received treatment in 17th August to 16th. All the parents, either mother or father of the children, available at the time of data collection were the sample size for this study. During the data collection period (24th April 2022 to 31st May 2022), 40 thalassemic children attended Narayani hospital for blood transfusion

After the approval of the research proposal from the research committee of TU, ethical approval ref no. 431(6-11) E2 018/079 was taken from the Institutional Review Committee of TU, IOM. Formal permission was taken from the Medical Superintendent, Matron and ward in-charge of the hospital for data collection. The objective of the study, their role in the study, confidentiality of the information and their right to discontinue was explained to each of the respondents meeting the eligibility criteria. Then written consent was obtained from the parents (either mother or father of children with Thalassemia) before data collection. Privacy was maintained by collecting data in a separate corner inside the nursing station. Data was collected through face-to-face interview technique by the two enumerators using self-constructed questionnaires. Confidentiality of the information was ensured by using code numbers and the information obtained would not be disclosed to others and only used for study purposes. The average time required to complete the interview was about 25-30 minutes. The duration of data collection was five weeks. Data was analyzed by using descriptive statistics i.e. frequency, percentage, mean, median, percentage, standard deviation. Inferential statistics, chi-square test was used to examine the association between independent and dependent variables.

The content validity was established with the help of extensive literature review, researcher knowledge and consultation with the pediatrician as expert. The instrument was translated to Nepali and backward translation was done with the help of bi-linguistic expert. After back translation, comparison between the backward version and the original version was done by the researcher to detect any mistranslations, inaccuracies or any misunderstandings in the forward version of the questionnaire. Nepali version of the questionnaire was used to collect data. Pretesting was done in 10% (4) of the estimated study sample who meet the inclusion criteria in Nepal Thalassemia Society Kathmandu, to check for clarity, applicability, any difficulties in their application and for completion of tools. After pretest no such significant modification was required in the tool.

RESULTS

In this study, about half (52.5%) of the respondents were of the age group ≤30 years of age, about one fourth (72.5%) of the respondents were the mother of Thalassemic child, two third (62.50%) of the respondents were from Parsa, about one third (32.5%) of the respondents belonged to Chaudhary caste group, more than two third (70.0%) of the respondents were from joint family. Almost half (47.50%) of the respondents' education level was primary level, three fourth (72.5%) of the respondents were housewife, and one fourth (25.0%) of the respondents had ≥ 4 children. Regarding thalassemia, almost three fourth (77.5%) of the respondents had only one Thalassemic child, about two third (62.5%) of the respondents had screened for Thalassemia, almost all (95.0%) of the respondents had no known family history of Thalassemia, few (15.0%) of the respondents had death of their child due to thalassemia and cent percent (100.0%) of the respondents had no known history of death of any other family member due to Thalassemia. Regarding consanguinity majority (95.0%) of the respondents had no history of consanguineous marriage in family and few (5.0%) of the respondents had consanguineous marriage.

Table 1: Demographic Characteristics of Thalassemic Child (n=40)

Variables	Number	Percentage
Age of child		
≤5 years	22	55.0
>5 years	18	45.0
Mean age ±Sd= 5.55±2.881		
Sex		
Male	24	60.0
Female	16	40.0
Age of diagnosis		
≤12 months	31	77.5
13-24 month	4	10.0
>24 month	5	12.5
Mean age ±Sd= 15±19.032		
Place of diagnosis		
Birgunj	25	62.5
Kathmandu	13	32.5
Others (Chitwan)	2	5.0
Thalassemia major	40	100.0
Blood transfusion is the treatment done	40	100.0
Frequency of blood transfusion		
2 weekly	5	12.5
3 weekly	1	2.5
4 weekly	34	85.0

Table 2: Respondents' Knowledge regarding Thalassemia (n=40)

Variables	Number	Percentage
Cause of thalassemia		
Genetic	9	22.5
Destiny	22	55.0
Don't know	9	22.5
Types of thalassemia*		
Minor	6	15.0
Major	33	82.5
Don't know	7	17.5
Organ affected by thalassemia		
Blood	29	72.5
Don't Know	11	27.5
Signs of thalassemia*		
Paleness	37	92.5
Loss of appetite	37	92.5
Weakness	37	92.5
Don't Know	1	2.5
Type of marriage that increases the risk of birth of thalassemic child		
Consanguineous Marriage	24	60.0

Don't Know	16	40.0
Heard about carrier		
Yes	4	10.0
No	36	90.0
Thalassemic carrier is as healthy as normal person (n=4)		
Yes	3	75.0
No	1	25.0
Can baby born from carrier parents have thalessamia (n=4)		
Yes	4	100.0
If one child is Thalassemic, there is chance of second baby being thalassemia		
Yes	26	65.5
No	7	17.5
Don't know	7	17.5

** Multiple responses*

Table 3: Respondents' Knowledge on Diagnosis and Treatment of Thalassemia (n=40)

Variable	Number	Percentage
Can a thalassemic child survive if left untreated		
Yes	6	15.0
No	32	80.0
Don't know	2	5.0
Diagnosis of thalassemia is done by		
Blood test	39	97.5
Don't know	1	2.5
Regular tests that should be done by thalassemic child *		
Haemoglobin level	33	82.5
Iron blood level	8	20.0
Kidney function Test	1	2.5
Liver function Test	1	2.5
Don't know	7	17.5
Diagnosis is made in hospital	40	100.0
Is blood transfusion the only treatment of thalassemia		
Yes	4	10.0
No	32	80.0
Don't know	4	10.0
Treatment modalities *		
Blood transfusion	39	97.5
Iron chelation	28	70.0
Splenectomy	2	5.0
Bone Marrow Transplant	5	12.5
Gene therapy	3	7.5
Can thalassemia be fully treated		
Yes	1	2.5
No	30	75.0
Don't Know	9	22.5
Blood transfusion is required every 2-4 weekly	40	100.0

Table 4: Respondents Knowledge on Complication and Prevention of Thalassemia (n =40)

Variable	Number	Percentage
Disease transmitted by blood transfusion*		
HIV	7	17.5
Hepatitis	6	15.0
Don't Know	32	80.5
Complication of repeated blood transfusion is iron overload		
Yes	12	30.0
No	28	70.0
Prevention of thalassemia in next pregnancy		
Parental Screening	6	15.0
Antenatal Screening	6	15.0
Don't know	29	72.5
Prevention of thalassemia		
Premarital Screening	3	7.5
Prenatal Screening	10	25.0
Antenatal Screening	4	10.0
Don't Know	26	65.0

Table 5: Level of Knowledge of Respondent regarding Thalassemia (n=40)

Level of Knowledge	Number	Percentage
Inadequate (<50%)	30	75.0
Adequate (≥50%)	10	25.0
Total	40	100.0

Table 6: Association between Socio-demographic Variables with Level of Knowledge (n=40)

Variables	Level of Knowledge		Chi Square Value	*P value*
	Inadequate	Adequate		
Age				
<30	18(85.7)	3(14.3)	1.637	0.201
≥30	12(63.2)	7(36.8)		
Relation with child				
Father	6(54.5)	5(45.5)	2.048	0.152
Mother	24(82.8)	5(17.2)		
Religion				
Hindu	26(76.5)	8(23.5)	0.000	1.060
Muslim	4(66.7)	2(33.3)		
Type of family				
Single	10(83.3)	2(16.7)	0.159	0.690
Joint	20(71.4)	8(28.6)		
Education				
Illiterate	11(91.7)	1(8.3)	1.429	0.232
Literate	19(67.9)	9(32.1)		
Occupation				
Housewife	24(82.8)	5(17.2)	3.386	0.109
Others	6(54.5)	5(45.5)		

DISCUSSION

This study aimed to assess the knowledge regarding Thalassemia among parents of children with Thalassemia in a tertiary hospital. In this study about one fourth (22.0%) of the respondent answered correctly that genetics is the cause of Thalassemia whereas in contrast to this in a study done in Iraq 53.9% of the respondents answered Thalassemia is a genetic Disease.[1] In contradictory to this finding in a study conducted in India by Kalra et al in 2019, 47.6% of the respondents replied genetics as the cause of Thalassemia which is the correct answer[8]. This difference might have occurred due to the difference in the sampling population. Majority of the respondents (82.5%) answered Thalassemia Major as the types of Thalassemia.

Almost three-fourth (72.5%) of the respondents answered blood as the organ affected by Thalassemia while contradictory to this finding 52.9% of the respondents in a study in Bangladesh by Hoissain et. al, 2001 answered blood or circulatory system is the part of the human body affected by Thalassemia.[11] This difference might have occurred as most of the parents had been transfusing blood to their children with Thalassemia in this study so they were aware about this fact. In this study majority (92.5%) of the respondents answered paleness, loss of appetite and weakness as the sign of Thalassemia whereas in a study titled Awareness among Parents of Beta Thalassemia Major and Intermedia Patients in Three Centers in Baghdad and Al-Nasiriyah, Iraq 86.0% of the parents answered yellowish discoloration as the sign of Thalassemia.[1]

Almost two third (60.0%) of the respondents in this study answered consanguineous marriage is the risk factor for Thalassemia. Similar to this finding in a study titled Knowledge, Attitude, Practices among Parents of B Thalassemia Children Regarding Thalassemia, 56.5% of the respondents answered consanguineous marriage increases the risk factor for Thalassemia.[12] Majority (90.0%) of the respondents had not heard about carrier status of Thalassemia whereas contrast to this finding 70.0% of the respondents had not heard about thalassemia carrier in a study conducted by Ebrahim et al.[13]

In this study few 5.0% and 12.5% had knowledge regarding splenectomy and bone marrow transplantation as the treatment of Thalassemia while in contrast to this finding, in a study Knowledge of the Caregivers of Thalassemic Children Regarding Thalassemia, 19.2% and 2.7% had knowledge regarding splenectomy and bone marrow transplantation.[9] In this study, only few (2.5%) of the respondents replied that thalassemia can be cured. Contradictory to this finding in a study titled the Parental Perspective of Thalassaemia in Bangladesh: lack of knowledge, Regret, and Barriers, 67.7% of the respondents answered that Thalassemia is a completely curable disease.[11] Contrast to this study finding in a study in India (100.0%) of the respondents answered bone marrow transplantation as the sole treatment of thalassemia.[8]

In this study, more than two third (71.1%) of the respondents were unaware about the risk diseases transmitted by blood transfusion. Few 15% and 17.5% answered hepatitis and HIV respectively is transmitted by blood transfusion where as in a study done in Iraq, 56.9% and 37.3% agreed hepatitis and HIV respectively is transmitted by blood transfusion.[1] More than two third (70.0%) of the respondents in this study were unaware about iron overload as the complication of repeated blood transfusion while in a study titled Awareness of Parents Regarding the Beta Thalassemia Major Disease, 92% of the parents knew that iron over load is the complication of repeated blood transfusion.[14] This study revealed that more than two third (67.9%) of the respondents were unaware about the prevention of Thalassemia and more than two third (70.8%) of the respondents were unaware about the prevention of Thalassemia in next pregnancy. Contradictory to this finding 52.4% and 50.9% knew about premarital counselling and antenatal screening in a study conducted by Biswas et. al, in India[9]. In contrast to this, 76% of the parents knew that prenatal diagnosis could prevent the birth of thalassemic child in a study conducted in India in the year 2019.[10]

Three fourth (75.0%) of the respondents had inadequate knowledge and one fourth (25.0%) had adequate knowledge regarding Thalassemia contradictory to this finding 52.7% had satisfactory knowledge in a study conducted by Biswas et al. 2018.[9] Contrast to this, 63.4% had good level of knowledge, 35.0% had average knowledge and 1.6% had poor knowledge in another study by Williams 2017.[15] Cent percent (100.0%) of the respondents had received the knowledge regarding thalassemia from Health Personnel. There is no association between age of respondents, relation with child, religion, address, family type, education, occupation and income with level of knowledge. This result might be due to limited sample size in this study.

CONCLUSION

The study concludes that majority of the parent's level of knowledge regarding thalassemia is inadequate. The areas of major knowledge lacking were causes of thalassemia, carrier status, regular follow up investigations, treatment modalities, prevention. Level of knowledge was not associated with age, religion, residence, type of family, education, occupation, income. So, health education should be provided by the health personnel to the parents regarding causes of thalassemia, carrier status, regular follow up investigations, treatment modalities, prevention so that the children would receive proper management. Also parents will be able to prevent the birth of children with Thalassemia in their subsequent birth.

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