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Knowledge of the Caregivers of Thalassemic Children Regarding Thalassemia: A Cross-sectional Study in a Tertiary Care Health Facility of Eastern India

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Abstract:

BACKGROUND: Caregivers knowledge regarding thalassemia is one of the vital areas in the prevention of the disease. Studies related to caregivers knowledge and its sociodemographic predictors are very few in number which is helpful in designing interventions across different study settings.

OBJECTIVES: the study aimed to find out the knowledge level of caregivers of thalassemic children and its sociodemographic determinants.

MATERIALS AND METHODS: It was a cross-sectional observational study conducted in a thalassemia day care unit of Eastern India. The study included 328 caregivers of thalassemic children attending thalassemia day care unit during May 2015–April 2016. Data were analyzed using Statistical Package for the Social Sciences (SPSS) (version 16).

RESULTS: Out of 328 caregivers only 47.6% knew about genetic etiology of the disease, while only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively. Regarding treatment of the disease, 75.9% knew that both blood transfusion and iron chelation are the treatment of thalassemia, while only 19.2% and 2.7% of them had knowledge regarding splenectomy and bone marrow transplantation, respectively. Only 52.7% had satisfactory knowledge regarding the disease. In multivariable model, caregivers educational level (adjusted odds ratio, AOR-3.13 [1.87–5.25]), working status (AOR-2.18 [1.23–3.86]), place of residence (AOR-2.05 [1.19–3.52]), and socioeconomic class (AOR-2.11 [1.25–3.58]) were significant predictors of their knowledge.

CONCLUSION: Caregivers' knowledge regarding thalassemia was not at all satisfactory. Regular counseling of caregivers should be done addressing the knowledge lacunae's among them.

Keywords:

Antenatal screening, knowledge, premarital counseling, thalassemia

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Introduction

Thalassemia is a chronic debilitating disease affecting nearly 200 million people worldwide. The disease originates from genetic mutations in the gene responsible for globin chain biosynthesis which is a constituent of normal adult hemoglobin. It leads to ineffective erythropoiesis and finally results in anemia.[1]

Globally, there are about 240 million carriers of β-thalassemia.[2] India is a home to 30–40 million carriers of the disease, with nearly 12,000 infants being born every year with a major form of the disease[3,4] which in turn comprises 10% of the total number in the world.[5]

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Thalassemia is a disease which does not have any known cure. Prevention is the only way to reduce its burden. It is more cost-effective approach compared to the provision of optimal treatment to the victims of thalassemia. Thus, raising awareness regarding the disease is one of the critical strategies for its prevention.[6]

Caregivers are the persons who provide care at the time of distress or illness. In case of chronic illnesses like thalassemia, their role becomes more evident. Their knowledge regarding the disease not only influences their wards quality of life but also indirectly influences their quality of life too. A caregiver who has good knowledge regarding the disease can not only provide a better quality of care to his/her ward but also may act as a percolator of knowledge to the society in which he/she lives. Thus, it helps immensely in raising community awareness related to the disease. There were extensive researches going on different therapeutic aspects of thalassemia,[7-9] ignoring caregiver's knowledge regarding thalassemia, and its determinants which is vital in terms of prevention of the disease. With this background, the current study was designed to find out the knowledge level of caregivers of thalassemic children regarding thalassemia and its sociodemographic determinants. The findings of the study will enable policymakers to identify knowledge lacunae's of caregivers of thalassemic child and its determinants. It will help in designing suitable interventions for not only caregivers of thalassemia affected children but also society at large.

Materials and Methods

The study was a cross-sectional, observational, hospital-based study conducted in thalassemia day care unit of a medical college of West Bengal in the eastern part of India from May 2015–April 2016 among 328 caregivers of thalassemic children with a structured schedule by face-to-face interview method. Approval of respective Institutional Ethics Committees was taken before conducting the study. Informed written consent of each study participant was obtained before their participation.

Caregivers of thalassemic children who had attended thalassemia day care unit during the study period and consented to participate were included in the study. One day in a week was allotted for data collection. There were total 917 patients (thalassemic children) registered with the thalassemia unit at the beginning of the study. In the study period, 349 caregivers accompanying the patient could be approached of which 328 consented and participated in the study which was 35.7% of registered patients with a response rate of 93.9%. Only one caregiver per patient was conveniently chosen for the study. Before each interview study participants were asked if they were interviewed before, to prevent duplication.

The structured schedule consisted of sociodemographic and caregiver's knowledge-related questionnaire. At first, the schedule was drawn up in English followed by a translation in the local language (Bengali). The schedule was pretested among 30 caregivers of thalassemic children. Later on, these 30 caregivers were not included in the study. After making necessary modifications based on results of the pretesting, the final schedule was prepared and used for the study. In the final schedule, knowledge questionnaire comprised of knowledge of the cause of the disease, premarital counseling, antenatal screening, and treatment modalities of the disease. Scores of individual items of the knowledge questionnaire were as depicted in Table 1. Some operational definitions used in the study are as follows.

Caregiver

In the present study, any adult first-degree relative who accompanied the thalassemic child during a visit to the thalassemia unit of the hospital and currently living with and taking care of the patient was considered as a caregiver.

Table 1: Distribution of the study participants according to their knowledge regarding the disease (*n*=328)

Variable	Frequency (%)	Score
Do you know how this disease is caused?		
Yes	189 (57.6)	-
No	139 (42.4)	
Cause of thalassemia as specified by the caregiver		
Correct knowledge (genetic)	156 (47.6)	1
Incorrect knowledge (destiny/contact with other thalassemic)	33 (10)	0
Don't know	139 (42.4)	0
Have you ever heard about premarital counseling?		
Yes	172 (52.4)	1
No	156 (47.6)	0
Have you ever heard about antenatal screening?		
Yes	167 (50.9)	1
No	161 (49.1)	0
Do you know about the treatment of thalassemia?		
Yes	303 (92.4)	-
No	25 (7.6)	
Treatment modalities as specified by the caregiver*		
Only blood transfusion	54 (16.5)	1
Only iron chelation	0	1
Both blood transfusion and iron chelation	249 (75.9)	2
Splenectomy	63 (19.2)	1
Bone marrow transplantation	9 (2.7)	1
Don't know	25 (7.6)	0

*Multiple response

Socioeconomic status

Modified B.G. Prasad scale May 2016 was used to assess the socioeconomic status.[10]

Knowledge score

It was calculated by addition of scores they received for each knowledge item where higher score indicated a higher level of knowledge. The minimum and maximum attainable score were 0 and 7, respectively. Meanwhile, the minimum and maximum attained score was same as attainable scores.

Satisfactory knowledge

Those who had scored more than equal to 4 (median attained score) were considered as having satisfactory knowledge regarding the disease.

Statistical analysis

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS) (version 16, Chicago, USA). First, univariate analysis by Mann–Whitney U-test was done to ascertain the association between various sociodemographic attributes with the knowledge score. Then, logistic regression analysis was done to ascertain 1:1 strength of association between sociodemographic factors and satisfactory knowledge individually and in the multivariable model. In the multivariable logistic regression model, the variables were entered by forced entry method. The strength of association was assessed by odds ratio (OR) at 95% confidence interval. Statistical significance for all analyses was set at $P < 0.05$.

Results

Table 1 shows knowledge of caregivers regarding different aspects of thalassemia. The attained knowledge score had the mean ± standard deviation of 3.4 ± 1.5 and median (interquartile range) of 4(2-5). Only 52.7% of them had satisfactory knowledge regarding the disease.

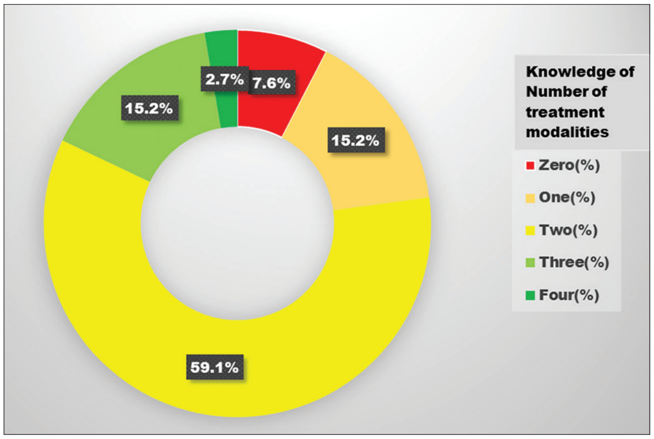

Figure 1: Distribution of the study participants according to their knowledge of number of treatment modalities of thalassemia ($n = 328$)

Majority of the study participants (59.1%) knew at least two treatment modalities of the disease [Figure 1].

The mean age of caregivers interviewed was 32.0 years (range: 21–56 years), while the mean age of the thalassemic children they were caring for was 8.0 (range: 5–12). Majority of the caregivers interviewed were mothers of the thalassemic child, residing in a rural area (72.3%), and belonged to socioeconomic Class IV and V (69.5%) with mean per capita income of 1643.4 rupees. Two-third of them was educated up to primary level with mean years of schooling of 5.3 years. Half of the caregivers (46.6%) were working for pay with the majority of them (94.7%) were doing unskilled/semi-skilled work, while 5 (3.3%) of them were professionals [Table 2].

In univariate analysis, caregivers' educational level, occupation, place of residence and socioeconomic status were found to be significantly associated with

Table 2: Socio-demographic characteristics of the study participants (*n*=328)

Variable	Frequency	%
Caregiver interviewed		
Father	78	23.8
Mother	246	75.0
Grandparents	4	1.2
Age of the caregiver in completed years		
21-24	24	7.3
25-28	86	26.2
29-32	105	32.0
33-36	41	12.5
39-40	42	12.8
≥41	30	9.1
Place of residence		
Urban	91	27.7
Rural	237	72.3
Religion		
Hindu	197	60.1
Muslim	129	39.3
Christian	2	0.6
Educational level of the caregiver		
Illiterate	76	23.2
Below primary	60	18.3
Primary	83	25.3
Middle	64	19.5
Secondary and above	45	13.7
Occupation of caregiver		
Not working	175	53.4
Work for pay	153	46.6
Socioeconomic status*		
Class II (3139-6276)	21	6.4
Class III (1883-3138)	79	24.1
Class IV (942-1882)	160	48.8
Class V (<942)	68	20.7

*According to modified B.G Prasad scale May 2016.

the knowledge regarding the disease. In multivariable model caregivers who were having higher educational level (adjusted OR, AOR-3.13 [1.87–5.25]), working for pay (AOR-2.18 [1.23–3.86]), residing in urban area (AOR-2.05 [1.19–3.52]), and belonged to higher socioeconomic class (AOR-2.11 [1.25–3.58]) had significantly higher odds of having satisfactory knowledge regarding the disease adjusted with their age, sex and religion. Overall, the model was explaining 17.8% variability of outcome variable with Hosmer–Lemeshow $P = 0.693$ indicating model fit and prediction accuracy rate of 59.9% [Tables 3 and 4].

Discussion

The study was a facility-based cross-sectional study exploring the knowledge level of caregivers regarding thalassemia and its sociodemographic predictors.

In the present study, only 47.6% of the caregivers knew that thalassemia is a genetic disease, which had similarities with findings of Saxena *et al*.[11] (47.5%), Ishaq *et al*.[12] (44.6%), and Maheen *et al*.[13] (55.2%). Meanwhile, the finding was better compared to Ishfaq *et al*.[14] (2013) (5.0%), Goyal *et al*.[15] (15.0%), and Arif *et al*.[16] (15.0%) but poor compared to findings of Ali *et al*.[17] (82.0%), Inamdar *et al*.[18] (68.5%), and Aggarwal[19] (60.2%). One-tenth of the study participants had misconceptions related to the causation of the disease (e. g., it is due to destiny, contact with other thalassemic, etc.). Studies conducted by Ghafoor *et al*.[20] and Maheen *et al*.[13] had also reported some misconceptions related to the causation of the disease (e.g., it can be transmitted sexually, through food, etc.) among caregivers, which was concurrent with our results.

Table 3: Association between socio-demographic characteristics and knowledge score of the study participants (*n*=328)

Variable	*n* (%)	Knowledge score mean±SD*	*P*†
Age in completed years			
≥30	175 (53.4)	3.5±1.5	0.216
<30	153 (46.6)	3.3±1.5	
Sex			
Female	249 (75.9)	3.5±1.5	0.156
Male	79 (24.1)	3.2±1.5	
Place of residence			
Urban	91 (27.7)	4.0±1.5	<.001
Rural	237 (72.3)	3.2±1.4	
Religion			
Hindu	197 (60.1)	3.5±1.6	0.214
Others	131 (39.9)	3.3±1.4	
Educational level			
Middle and above	109 (33.2)	3.9±1.6	<.001
Below middle	219 (66.8)	3.2±1.4	
Occupation			
Work for pay	153 (46.6)	3.8±1.4	0.024
Not working	175 (53.4)	3.3±1.5	
Socioeconomic status‡			
Class II and III	100 (30.5)	3.8±1.5	0.003
Class IV and V	228 (69.5)	3.3±1.5	

*Standard deviation, †Mann Whitney U test, ‡according to modified B.G Prasad scale May 2016

Only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively. The findings were more compared to Inamdar *et al*.[18] (31.4% and 45.0%) but less compared to Ishaq *et al*.[12] (84.3% and 76.5%).

Majority of the study participants (75.9%) knew that both blood transfusion and iron chelation are the treatment of thalassemia. The study conducted by Inamdar *et al*.[18] (77.1%) had reported similar observations.

In our study, 19.2% knew splenectomy as a treatment option of thalassemia which was worse compared to Goyal *et al*.[15] (66.0%). Knowledge of bone marrow transplantation was present in only 2.7% which was quite worse compared to findings of Inamdar *et al*.[18] (45.7%) and Ali *et al*.[17] (60.0%). Most of them (59.1%) knew about at least two treatment modalities of thalassemia, while 7.6% had no knowledge regarding any treatment modality. In the present study, 17.9% of the caregivers had knowledge of at least three or more treatment modalities of the disease which was in concordance with the findings of Goyal *et al*.[15]

Out of 328 caregivers of the study participants, only 52.7% had satisfactory knowledge regarding the disease which was similar to findings of Ghazanfari *et al*.[21] (50.0%) and Williams *et al*.[22] (63.4%). Meanwhile, Aggarwal[19] reported average knowledge related to management of thalassemia among caregivers. The variability of the results may be attributed to ethnicity, socioeconomic status, different proportion of gender in the sample, number of samples, and moreover, due to geographical plausibility.

Caregivers educational level emerged as a significant predictor of their knowledge regarding the disease which was in concordance with the findings of Ghazanfari *et al*.[21] but unlike findings of Williams *et al*.,[22] which did not find any such association. The cause of such finding may be with an increment of their educational level, their counseling readiness, and knowledge retention also improves.

In the present study, working caregivers had significantly higher odds of having satisfactory knowledge regarding the disease. The study conducted by Williams *et al*.[22] failed to demonstrate any such association. The variations in the study results may be due to geographical plausibility.

Table 4: Univariate and multivariable logistic regression analysis showing predictors of satisfactory knowledge of the study participants (*n*=328)

Variable	Satisfactory knowledge *n* (%)	OR[*] (95% CI[†])	*P*	AOR[‡] (95% CI[†])	*P*
Age (increasing)	-	0.99 (0.96-1.02)	0.589	0.99 (0.95-1.02)	0.640
Sex					
Female	133 (53.4%)	1.12 (0.67-1.85)	0.573	1.59 (0.79-3.23)	0.360
Male	40 (50.6%)	Reference		Reference	
Religion					
Hindu	111 (56.3%)	1.43 (0.92-2.24)	0.067	1.53 (0.95-2.49)	0.060
Others	62 (47.3%)	Reference		Reference	
Place of residence					
Urban	62 (68.1%)	2.43 (1.46-4.04)	0.001	2.05 (1.19-3.52)	0.016
Rural	111 (46.8%)	Reference		Reference	
Educational level					
Middle and above	76 (69.7%)	2.90 (1.78-4.72)	<.001	3.13 (1.87-5.25)	<.001
Below middle	97 (44.2%)	Reference		Reference	
Work for pay					
Yes	90 (58.8%)	1.58 (1.02-2.45)	0.045	2.18 (1.23-3.86)	0.010
No	83 (47.4%)	Reference		Reference	
Socioeconomic status[§]					
Class II and III	63 (63.0%)	1.83 (1.13-2.96)	0.013	2.11 (1.25-3.58)	0.008
Class IV and V	110 (48.2%)	Reference		Reference	

[*] Odds ratio, [†] confidence interval, [‡] adjusted odds ratio, [§] according to modified B.G Prasad scale May 2016

Those who were residing in urban areas had significantly higher odds of having satisfactory knowledge of the disease. It may be due to the higher level of education in the urban area which may have resulted in such association.

Caregivers who belonged to higher socioeconomic status were more likely to have satisfactory knowledge regarding the disease. It was unlike findings of Williams *et al*.[22] which did not find any such association between family monthly income and knowledge of caregivers. The variability of the results of Williams *et al*.[22] with our study may be due to its small sample size compared to us. The possible explanation of such finding could be a caregiver who belongs to a higher socioeconomic class is likely to be more educated and aware and vice versa.

The significant limitations of the study were its cross-sectional design, self-reported data, etc. There may be under- or overreporting and chances of social desirability bias cannot be overlooked.

Conclusion

Caregivers' knowledge regarding thalassemia was not at all satisfactory. At every given opportunity, the lacunae's in the knowledge of caregivers of the thalassemic child should be addressed by arranging regular counseling sessions and awareness generation campaigns in an easily comprehensible vernacular language with frequent reinforcements.

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Conflicts of interest

There are no conflicts of interest.

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