Original Article

A study on awareness among parents with beta thalassemia major children in government district hospital, Kalaburagi

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ABSTRACT

Background: Thalassemia is a public health problem worldwide. With the high disease burden of thalassemia, low socioeconomic conditions and poor preventive strategies, our patients are left with no other option except the repeated blood transfusion. So prevention is the only tool to reduce the burden of this disease. This study was done to identify the gap in knowledge, attitude and practices (KAP) about β-thalassemia among the parents of beta thalassemia children. So that it will be helpful to reduce the burden of the disease in the society in the near future. **Objectives:** To assess the Knowledge (K), attitude (A) and practices (P) among parents with beta thalassemia major children regarding beta thalassemia major disease. **Materials and Methods:** A semi structured pre-validated questionnaire designed to assess the Knowledge, Attitudes and Practices in relation to beta thalassemia major disease was administered to all the parents fulfilling the inclusion criteria. Collected data was analysed. **Results:** In this study, None of the participants had knowledge about thalassemia before their first child was born. In this study, 76.9% study subjects knew and understood the genetic nature of Thalassemia. In our study, about 75.4% participants didn't know about premarital screening and 50.8% didn't know about prenatal diagnosis. About 18.5% of them are practising chorionic villous sampling test. Only 60.0% of them got other siblings of the thalassemia children screened for thalassemia. Only 43.1% received genetic counselling about thalassemia major. **Conclusion:** It was seen from our study that parents don't have adequate knowledge, positive attitude and practice on thalassemia major. Health education and periodic counselling of parents and care takers about prevention of thalassemia needs to be implemented at every thalassemia day care centre.

Key words: Awareness, Thalassemia Major, Parents, Knowledge, Practices

Beta thalassemia is one of the most common single-gene inherited condition in the world.[1]Thalassaemia major is an inherited blood disorder, which can be defined as "the inability of the human body to produce sufficient amount of hemoglobin in red blood cell" thus resulting in severe anaemia.[2]

Various studies show that around 70,000 infants are born with beta thalassemia worldwide every year, and 270 million people are carriers of haemoglobinopathies.[3] Due to its high prevalence, Thalassemia is a public health problem worldwide, which is particularly common in the Mediterranean as well as in Southeast Asia, Africa and Middle East[1] with reported rates ranging from 2 to 25%.[4]

With the high disease burden of thalassemia, low socio economic conditions and poor preventive strategies, our patients are left with no other option except the repeated blood transfusion, which inadvertently results in high chances of infections like hepatitis B and C, iron overload and other immunological responses.[5] This affects the patient's physical, emotional and school functioning leading to an impaired quality of life and also causes tremendous financial burden to their families.[6] The definitive cure of thalassemia is bone marrow transplant, this facility is available only in very few centers in India. So prevention is the only way to reduce the burden of disease in thalassemia. The main prevention strategies comprise of providing appropriate information to the public and professionals, screening and counseling of families at risk and screening of couple prior to marriage.[7]

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The Policy For Prevention and Control of Hemoglobinopathies – Thalassemia, Sickle Cell Disease and variant Hemoglobins in India (by Ministry of Health and Family Welfare), 2018, encompasses the vision to enable access to affordable and quality care to all patients with Thalassemia, HbE and Sickle Cell Disease, and also to lower the prevalence of hemoglobinopathies through awareness and screening programs.[8]

The purpose of this study is to assess the awareness about thalassemia major disease among parents with thalassemia children and to identify the gap in knowledge, attitude and practices (KAP) about β-thalassemia among the parents of beta thalassemia children. So that it will be helpful to reduce the burden of the disease in the society in the near future.

MATERIALS AND METHODS

This cross sectional descriptive study was conducted over a period of 3 months (from July 2023 to September 2023) among 65 parents of beta thalassemia major children attending department of Pediatrics, Gulbarga institute of Medical sciences, Kalaburagi. The study was conducted after obtaining the ethics committee approval from Institutional Ethics committee. Informed consent was obtained from all eligible participants after explaining the objectives and nature of this study in their own language. A semi structured pre-validated questionnaire designed to assess the Knowledge, Attitudes and Practices in relation to beta thalassemia major disease was administered to all the parents fulfilling the inclusion criteria.

The data collected through this questionnaire includes: socio demographic details of parents and children and various information to assess the KAP of parents with respect to thalassemia major disease like, about nature of the disease, about premarital screening, prenatal diagnosis, genetic counseling, iron chelation therapy, hepatitis B vaccination and data related to parents attitude and practices about beta thalassemia major.

Statistical data was analyzed by using statistical package for social sciences (SPSS, version 25.0). If p value is <0.05, it is considered statistically significant.

RESULTS

In the study, the mean age of participants observed was 33.84 years. Majority of participants 31 (47.7%) were belonging to the age group of 31 to 40 years, The male (father) participants were 36 (55.4%) and female (mother) participants were 29 (44.6%). Majority of participants 45 (69.2%) residential area was rural.

Majority of participants 38 (58.5%) were belonging to the socio-economic status of lower class, followed by 24 (37.0%) were belonging to lower middle class and 3 (4.5%) of the participants were belonging to middle class, no participants were seen in upper middle class and upper class. Out of 65 participants; 22 (33.8%) participants were illiterate, 13 (20.0%) had primary education and 30 (46.2%) had secondary and degree education. Majority of participants 38 (58.4%) were Daily wage workers.

Table 1: Socio Demographic profile of study participants

Variables	Categories	No. of Participant	Percentage
Age of participant	**20—30 years**	27	41.5
	31—40 years	31	47.7
	41—50 years	7	10.8
	Mean ± SD	33.84 ± 7.54	----
Gender of participant	**Male**	36	55.4
	Female	29	44.6
Area of residence	**Urban area**	20	30.8
	Rural area	45	69.2
Religion/ caste	**Muslims**	6	9.2
	General	6	9.2
	OBC	18	27.7
	SC/ST	35	53.9
Socio-economic status (B G Prasad classification) 9	**Upper Class**	0	0.0
	Upper Middle Class	0	0
	Middle Class	3	4.5
	Lower Middle Class	24	37.0
	Lower Class	38	58.5
Educational status of participant	**Illiterate**	22	33.8
	Primary	13	20.0
	Secondary and degree	30	46.2
Occupation of participant	**House wife**	23	35.4
	Daily wage worker	38	58.4
	Employed	4	6.1

Table 2 shows Knowledge of participants regarding thalassemia. None of the participants had knowledge about thalassemia before their first child was born. When the participants were asked about cause of thalassemia, majority of them 50(76.9%) said that it is a genetic/Inherited disorder and 15(23.1%) said that they don't know what causes thalassemia. Majority of them 46(70.0%) didn't know the reasons and risk factors of thalassemia and 19(29.2%) knew that Positive Family history is a risk factor for thalassemia.

When the participants were asked for treatment options of thalassemia, 29(44.6%) said both blood transfusion and bone marrow transplant, 28(43.1%) said only Blood transfusion and 8(12.3%) did'nt know any of the treatment options for thalassemia. About 34(52.3%) participants didn't know the role of consanguinity in thalassemia.

Table 2: Knowledge of participants regarding Thalassemia major

SL No	Knowledge questions	Answer	No.	%
1	Did you know about thalassemia before first child?	No	65	100.0
		Yes	0	0.0
2	What kind of disease is thalassemia?	Don't know	15	23.1
		A genetic/Inherited disorder	50	76.9
		Infectious disease	0	0.0
		Any other	0	0.0
3	Do you know the reasons and risk factors of thalassemia?	Don't know	46	70.0
		Positive Family history	19	29.2
		Poor health at birth	0	0.0
		Any other	0	0.0
4	Do you know the treatment options for thalassemia?	Don't know	8	12.3
		Blood transfusion	28	43.1
		Blood transfusion and bone marrow transplant	29	44.6
5	Do you know the role of consanguinity in thalassemia?	Don't know	34	52.3
		Not necessary	17	26.2
		Yes	14	21.5
6	Do you know about premarital screening?	No	49	75.4
		Yes	16	24.6
7	Do you know about prenatal diagnosis?	No	33	50.8
		Yes	32	49.2
8	Do you know about blood transfusion is needed to the patient throughout life?	No	0	0.0
		Yes	65	100.0
9	Do you know about prevention of thalassemia?	Don't know	33	50.8
		Genetic counseling	15	23.1
		Premarital screening	24	36.9
		Prenatal diagnosis	30	46.1
10	Do you know about iron overload because of repeated transfusions?	No	28	43.1
		Yes	37	56.9
11	Do you know about Iron chelation therapy?	No	34	52.3
		Yes	31	47.7
12	Do you know about the risk of getting Hepatitis B because of repeated transfusion?	No	28	43.1
		Yes	37	56.9
13	Do you know about Hepatitis B vaccine?	No	55	84.6
		Yes	10	15.4

49(75.4%) didn't know about premarital screening and 33(50.8%) didn't know about prenatal diagnosis. All of them knew that blood transfusion is needed to the thalassemia major patient throughout life.

When the participants were asked about prevention methods of thalassemia, 33(50.8%) didn't know any of the prevention methods, 15 (23.1%) said genetic counseling, 24(36.9%) said premarital screening and 30(46.1%) of them said prenatal diagnosis as the methods to prevent thalassemia.

About 28(43.1%) didn't have any knowledge about iron overload because of repeated transfusions in thalassemia. About 34(52.3%) didn't know about iron chelation therapy in thalassemia, About 28(43.1%) didn't know about the risk of getting Hepatitis B because of repeated transfusion and 55(84.6%) didn't know about Hepatitis B vaccine.

Table 3: Attitude of participants regarding Thalassemia major

SL No	Survey questions	Decision	No.	%
1	Do you feel that two thalassemia carrier's should marry?	Yes	0	0.0
		No	65	100.0
2	Do you feel that carrier couple should have children?	Yes	0	0.0
		No	65	100.0
3	Do you feel that Premarital screening is necessary for general public?	Yes	34	52.3
		No	31	47.7
4	Do you feel termination of pregnancy due to Thalassemia major in fetus should be done?	Yes	60	92.3
		No	5	7.7
5	Does taking Hepatitis B Vaccination is good to your child?	Yes	36	55.4
		No	13	20.0
		Don't know	16	24.6

Table 3 shows Attitude of participants regarding thalassemia, All of them said that two thalassemia carrier's should not marry and all of them are of the opinion that carrier couple should not have children. About 34(52.3%) felt that Premarital screening is necessary for general public. About 60(92.3%) felt that termination of pregnancy due to Thalassemia Major in fetus should be done. 36(55.4%) of them said that taking Hep B Vaccination is good to their child.

Table 4: Practice of participants regarding Thalassemia major

SL No	Practice questions	Opinion	No.	%
1	Did you get screened for thalassemia?	Yes Both(mother and father)	18	27.6
		Yes Only Father	0	0.0
		Yes Only Mother	0	0.0
		Not Tested	47	72.3
2	Are you practising chorionic villous sampling test?	Yes	12	18.5
		No	53	81.5
3	Did you get other siblings of the thalassemia child screened for thalassemia?	Yes	39	60.0
		No	26	40.0
4	Do you wish for having more children although one children is sick?	Yes	4	6.2
		No	61	93.8
5	Does the Child's disease known to the relatives?	Yes	58	89.2
		No	7	10.8
6	Do you practice sharing of food with Thalassemia child?	Yes	65	100.0
		No	0	0.0
7	Did you receive genetic counseling?	Yes	28	43.1
		No	37	56.9
8	Did your child took hepatitis B Vaccination in the past five years?	Yes	5	7.6
		No	60	92.3

Table 4 shows Practice of participants regarding Thalassemia major, About 47(72.3%) had not been screened for thalassemia, About 18(27.6%) got both mother and father screened for thalassemia. About 12(18.5%) of them are practising chorionic villous sampling test. Only 39(60.0%) of them got other siblings of the thalassemia children screened for thalassemia. Majority of them 61(93.8%) told that they are not wishing for having more children although one children is sick.

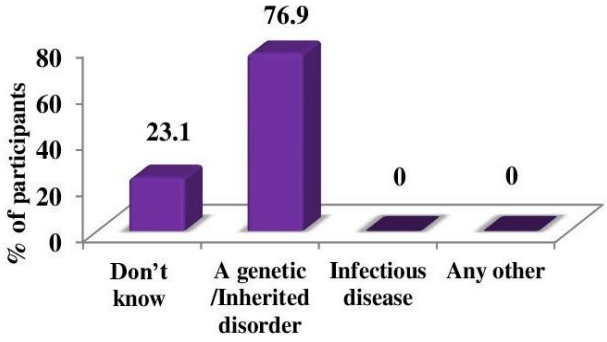

Fig 1: Knowledge about the cause of Thalassemia major

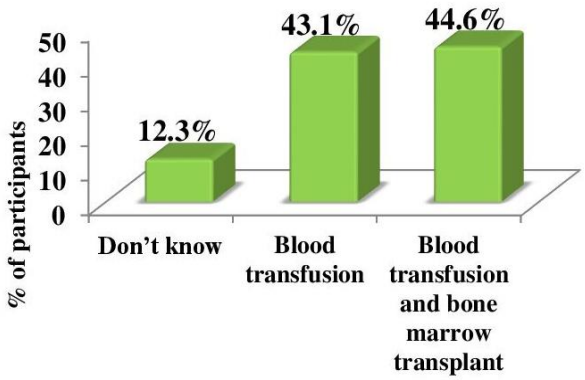

Fig 2: Participants knowledge with respect to treatment options for Thalassemia Major

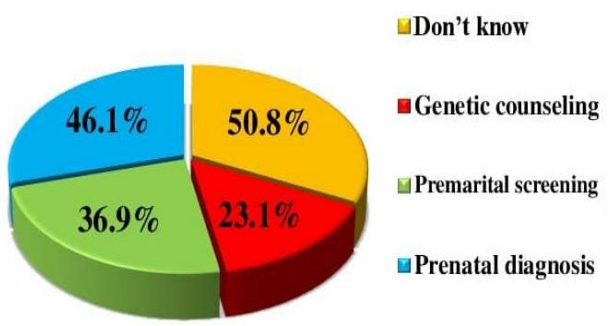

Fig 3: Pie diagram represents prevention of thalassemia

About 7(10.8%) of them didn't disclose the Child's disease to the relatives. All of them practice sharing of food with the thalassemia child. Only 28(43.1%) received genetic counseling about thalassemia major. Only 5(7.6%) children took hep B Vaccination in the past five years.

DISCUSSION

Thalassemia is a hereditary hemoglobinopathy and a chronic disorder so prevention of thalassemia is utmost important aspect to reduce the burden on society, for these social scientists, doctors and counselors should play a major role in prevention. Usually government hospital of tertiary level in all states are often over-crowded with these patients and parents of these thalassemia patients needs to be counseled and sustained motivation to parents of children suffering from thalassemia is often needed. Doctors and counselors should focus on to serve these people from simple infections to long lasting chronic illnesses. Government should take initiation to give enough support in providing counselors for these disorders.[10]

In our study, Majority of participants 31 (47.7%) were belonging to the age group of 31 to 40 years, The male (father) participants were 36 (55.4%) and female (mother) participants were 29 (44.6%). Majority of participants 45 (69.2%) residential area was rural. In the current study, we

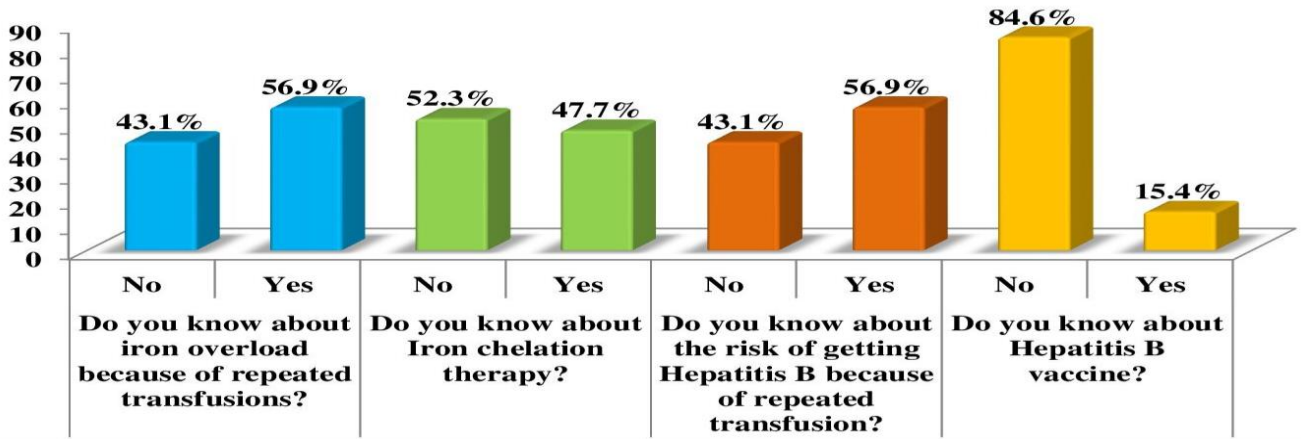

Fig 4: Knowledge of participants regarding Thalassemia major

had a slight male preponderance of Thalassemia with 41(63.1%) males and 24(36.9%) females. A study by Goyal JP A et al, and Saxena A et al, showed a male preponderance similar to in this study.[11,12] However, the study conducted in Pakistan by Arif F et al, showed a slight female preponderance.[13]

In this study, None of the participants had knowledge about thalassemia before their first child was born. In this study, 76.9% study subjects knew and understood the genetic nature of Thalassemia. This knowledge was better than that in the studies conducted by Biswas B et al, (47.6%), Saxena A et al, (47.5%) but lesser than the study conducted by Arif F et al, (82%).[12,13,14]. Majority of them,70.0% didn't know the reasons and risk factors of thalassemia and 29.2% knew that Positive Family history is a risk factor for thalassemia.

In our study,44.6% of the participants knew that both blood transfusion and bone marrow transplant are the treatment options for thalassemia major,43.1% knew only Blood transfusion as the treatment option ,12.3% did'nt know any of the treatment options for thalassemia. Where as in the studies conducted by Saxena A et al, 62.5% knew about the need of blood transfusion and in the study conducted by Biswas B et al, only 75.9% knew. [12,14] About 52.3% participants didn't know the role of consanguinity in thalassemia. In our study, about 75.4% participants didn't know about premarital screening and 50.8% didn't know about prenatal diagnosis. Where as in the study conducted by Biswas B et al , 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively.[14]

In our study, about 56.9% had knowledge about iron overload because of repeated transfusions in thalassemia and 47.7% knew about iron chelation therapy in thalassemia . In the study by Goyal JP et al, most of them knew about iron overload.[11] comparatively better results were seen in the study conducted by Kalraa RK et al where 100% knew about the reactions to the blood being transfused and 100% knew that iron overload could be a potential complication of repeated transfusions and 100% subjects knew that iron chelation therapy is needed for the treatment. [15] About 56.9% knew about the risk of getting Hepatitis B because of repeated transfusion and 15.4% knew about Hepatitis B vaccine. Where as in the study conducted by Kalraa RK et al 100% subjects knew the importance of hepatitis B vaccination in chronically transfused patients.[15]

In our study, when attitude of participants regarding thalassemia was assessed, All of them said that two thalassemia carrier's should not marry and all of them are of the opinion that carrier couple should not have children. About 52.3% said that Premarital screening is necessary for general public.About 92.3% said that termination of pregnancy due to Thalassemia Major in fetus should be done. In the study conducted by Basu M, about 99.06% of the participants viewed that premarital screening for thalassaemia carrier is necessary and about 81.31% believed that it is better to terminate pregnancy than to let the child suffer after he/she is born.[16]

In our study, Practice of participants regarding Thalassemia major showed that, About 18.5% of them are practising chorionic villous sampling test. Only 60.0% of them got other siblings of the thalassemia children screened for thalassemia. Only 43.1% received genetic counselling about thalassemia major. About 60% knew the importance of screening but only 27.5% underwent screening for the next pregnancy in the study by Saxena A et al. [12]In a study conducted by Basu M, About 12.38% participants had pre marriage counselling and 4.9% had Prenatal diagnosis during pregnancy. [16] In our study, only 7.6% of the children took hepatitis B Vaccination in the past five years. About 42% were completely immunized against hepatitis B in the study by Goyal JP et al.[11]

From our study, it was found that, knowledge of the parents regarding the cause, course, complications

,management and prevention of Thalassemia is not adequate. This emphasizes the need for such a social worker/counsellor to be associated with every Thalassemia day care center so that it helps in creating awareness regarding this disease in the parents.

In our study, there is a lack of positive attitude and practice towards prevention of this disease in their subsequent child or in their near and dear ones. The major reason for this could be the lack of availability of prenatal diagnostic tests and genetic counseling in the local hospitals. This suggests that government sponsorship is needed to make prenatal diagnostic tests and genetic counseling available in the government set up so as to prevent the birth of thalassemic children and thereby decreasing the disease burden in the families as well as in our country.

CONCLUSION

It was seen from our study that parents don't have adequate knowledge, positive attitude and practices related to thalassemia major disease prevention and treatment; Health education and periodic counseling of parents and care takers about prevention of thalassemia needs to be implemented at every thalassemia day care centre. Dedicated social worker/counsellor should be associated with every thalassemia day care centre to counsell the parents and care takers of thalassemia major. And it is better to have a child psychologist in the thalassemia day care centre to take care of mental health of thalassemia major children.

The chronicity and complications of Thalassemia will affect the quality of life of the patients and their families. Majority of the families either cannot find a matched donor or cannot afford bone marrow transplantation, so they will depend on blood transfusions as the primary management, which creates a burden on the health system and also on the affected families. So prevention of this disease with adequate practice of prenatal diagnosis and premarital screening is necessary, which needs government sponsorship to make these prenatal diagnostic tests available in government set up so that disease burden in the families as well as in the country can be reduced.

REFERENCES

1. Cousens NE, Gaff CL, Metcalfe SA, Delatycki MB. Carrier screening for beta-thalassaemia: a review of international practice. Eur J Hum Genet. 2010; 18:1077-83.
2. Chui DH, Cunningham MJ, Luo HY, Wolfe LC, Neufeld EJ, Steinberg MH. Screening and counseling for thalassemia. Blood. 2006; 107:1735-7.
3. Aabolghasemi H, Amid A, Zeinali S, Radfar MH, Eshghi P, Rahiminejad MS, et al. Thalassemia in Iran: epidemiology, prevention, and management. J Pediatr Hematol Oncol. 2007; 29:233-8.
4. Najmabadi H, Karimi-Nejad R, Sahebjam S, Pourfarzad F, Teimourian S, Sahebjam F, et al. The beta-thalassemia mutation spectrum in the Iranian population. Hemoglobin. 2001; 25:285-96.
5. Dehkordi AH, Heydarnejad MS. Effect of booklet and combined method on parent's awareness of children with beta-thalassemia major disorder. J Pak Med Assoc. 2008; 58(9):485-7.
6. Aggarwal K. A Study to assess the Knowledge of Parents of thalassemic Children in the age group of 2-7 years attending thalassemic Ward of a Selected Hospital of Delhi, regarding management of thalassemia. Int J Nurs Midwifery Res. 2016;3(1):36-40.
7. Bryan S, Dormandy E, Roberts T, Ades A, Barton P, Juarez-Garcia A, et al. Screening for sickle cell and thalassaemia in primary care: A cost-effectiveness study. Br J Gen Pract.2011; 61:591.
8. Verma IC, Ghosh K, Colah R, Gatpylee AK. The Policy For Prevention and Control of Hemoglobinopathies –Thalassemia, Sickle Cell Disease and variant Hemoglobins in India. Ministry of Health and family welfare. New Delhi. 2018. Available at: https://mohfw.gov.in/sites/default/files/drft%20policy.pdf. Accessed 5 April 2024.
9. Mangal A, Kumar V, Panesar S, Talwar R, Raut D, Singh S. Updated BG Prasad socioeconomic classification, 2014: A commentary. Indian J Public Health 2015;59:42-4.
10. Bandyopadhyay B, Nandi S, Mitra K, Mandal PK, Mukhopadhyay S, Biswas AB. A Comparative study on perceptions and practices among parents of thalassemia children attending two different institutions. Indian Journal of Community Medicine. 2003; 28(3):128-132.
11. Goyal JP, Hpapani PT, Gagiya H. Awareness among parents of children with thalassemia major from Western India. Int J Med Sci Public Health. 2015;4(10):1356-60.
12. Saxena A, Sharif M, Siddiqui S, Singh S. Knowledge practice and experiences of parents with a thalassemic child. Int J Contemp Pediatr. 2017;4(5):1630-3.
13. Arif F, Fayyaz J, Hamid A. Awareness among parents of children with thalassemia major. J Pak Med Assoc. 2008;58(11):621-4.
14. Biswas B, Naskar NN, Basu R, Dasgupta A, Paul B, Basu K. Knowledge of the caregivers of thalassemic children regarding thalassemia: A cross-sectional study in a tertiary care health facility of eastern India. Iraqi J Hematol. 2018;7(2):49.
15. Kalra RK, Kaur D, Sodhi M, Kaur J. Knowlegde, attitude and practice in parents of chronically transfused thalassemic patients regarding thalassemia in thalassemia day care unit in government medical college, Amritsar, Punjab, India. Int J Contemp Pediatr 2019;6:2469-75.
16. Basu M. A study on knowledge, attitude and practice about thalassemia among general population in outpatient department at a Tertiary Care Hospital of Kolkata. J Prev Med Holist Health. 2015;1(1):6-13.

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