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Original Research Article

Knowledge, attitude and practice in parents of chronically transfused thalassemic patients regarding thalassemia in thalassemia day care unit in government medical college, Amritsar, Punjab, India

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ABSTRACT

Background: Thalassemia is a chronic debilitating disease that affects nearly 200 million people worldwide. 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 spread knowledge in the society in which he/she lives which helps immensely in raising community awareness related to the disease.
Methods: 50 caregivers (either mother or father) of chronically transfused thalassemic children were questioned regarding their knowledge, attitude and practice towards this disease, using a self-constructed questionnaire.
Results: It was found that despite adequate knowledge regarding every aspect of this disease, there is a lack of attitude of practice towards prevention of this disease in their subsequent child or in their near and dear ones.
Conclusions: There is a need to promote an attitude of practice in prevention of the birth of thalassemic children as mere knowledge regarding the disease is not enough in the present scenario where the disease burden is increasing as is the financial and emotional burden on the families. Role of Government sponsorship, a social worker and a child psychologist in the Thalassemia day care unit cannot be minimized.

Keywords: Antenatal screening, Awareness, Blood transfusion, Day care center, Iron chelation, Thalassemia

INTRODUCTION

Thalassemia is an inherited (autosomal recessive) impairment of haemoglobin production, in which there is partial or complete failure to synthesise a specific type of globin chain, alpha chain in alpha-thalassemia and beta chain in beta-thalassemia. Thalassemia should be considered in the differential diagnosis of any child with hypochromic, microcytic anemia that does not respond to iron supplementation. Children with beta-thalassemia, most common type, usually develop no symptoms until about 3-6 months of age. Severe pallor and hepatosplenomegaly are almost always present. Symptoms of severe anemia, like intolerance to exercise, irritability and heart murmur or even signs of heart failure may be present.[1,2]

This chronic debilitating disease affects nearly 200 million people worldwide with males and females having a similar rate.[3,4] India is 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 which in turn comprises 10% of the total number in the world.[3]

Management of the patients includes regular blood transfusions to keep Hb above 9-10gm/dl, iron chelation therapy to reduce iron overload and surgical interventions like splenectomy. Allogenic hematopoietic transplantation is the definitive curative treatment available till date.[5] The effect of Thalassemia on the body can lead to physical deformity, growth retardation and delayed puberty. Its impact on the patient's appearance, like bone deformity and short stature, also contributes to a poor self-image.

This not only affects the patient's physical functioning but also their emotional and school functioning leading to an impaired quality of life. Presence of a sick child in the family paves way for the family's change of behavior and increases their financial burden.[6] Hence, in case of chronic illnesses like thalassemia, the role of caregivers becomes more evident. Their knowledge regarding the disease not only influences their wards quality of life but also indirectly influences their own. 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 spread knowledge in the society in which he/she lives which helps immensely in raising community awareness related to the disease.[3]

This traumatic disorder is inherited to the next generation due to the parent's ignorance, which can be prevented by carrier screening, premarital counseling, prenatal diagnosis and generating awareness amongst masses. Premarital screening is a successful approach for Thalassemia prevention but is not feasible in India because of social and cultural taboos and non-availability of screening and diagnostic services to a large portion of population residing in remote places inaccessible to health services.[7]

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 to lower the prevalence of hemoglobinopathies through awareness and screening programs.[8]

In addition, there are several National Institutions, Medical Colleges, Central and State Government supported programs as well as Thalassemia Societies and non-governmental organization groups involved in efforts for generating awareness on the hemoglobinopathies as well as conducting epidemiological studies.[9]

They are working towards achieving their common goal, which is controlling the incidence and prevalence of Thalassemia as this Policy of 2018.

Through this observational study, we want to find out the level of awareness and understanding of Thalassemia, its cause, management and complications, in the parents of a child living with this disease and their attitude of practice in prevention of Thalassemia, in order to improve the course and outcome of the disease and prevent the birth of further diseased children.

The objevtive of this study to know the knowledge, attitude and practice in parents of chronically transfused Thalassemic patients visiting the day care center of Government Medical College, Amritsar, Punjab, India.

METHODS

Study protocol was approved by the institutional Ethics committee of Government Medical College, Amritsar. It was an observational, hospital-based study conducted from 1st June to 30th June 2019 in the Thalassemia day care center of Government Medical College, Amritsar, Punjab, India.

Thalassemic children visit this center for regular blood transfusions accompanied by their parents. 50 study participants were chosen at random from either of the parents accompanying these children (whoever was available). After taking the informed consent, information was gathered on a self-constructed questionnaire (translated into local language, Punjabi) and data analysis was done.

Inclusion criteria

Parents of children diagnosed with Thalassemia major who bring their children for regular blood transfusion to this center.

Exclusion criteria

- Parents of children with Thalassemia minor
- Parents of children with Thalassemia major with other co-morbidities like hypothyroidism, diabetes mellitus or any other
- Caregivers other than the parents

RESULTS

In this study, a total of 50 subjects (either parent) were enrolled, out of which 12 (24%) were females (mothers) and 38 (76%) males (fathers). Mean age of the subjects was 36.02 years with maximum and minimum being 56 years and 22 years respectively. Age distribution showed majority of them were in the age group 31-40 years (40%). Illiteracy rate among the subjects was 36%. 24% had primary education, 6% middle education, 16% high school education, 12% were educated to graduate level and 6% to post-graduate level (Table 1). Illiteracy was higher in males (22%) than females (14%). Out of the total, 24% were unemployed (all females) while the males (76%) were employed as an unskilled worker

(22%), skilled worker (28%), shop owner/clerical worker/farmer (22%) or as a professional (4%) (Table 1). According to the Kuppuswamy socio-economic scale, socio-economic status of the study subjects was calculated, and it was found that 8% subjects were in the lower class, 42% in the upper lower class, 40% in the lower middle class and 10% in the upper middle class (Figure 1).

Knowledge of the study subjects regarding the cause and course of Thalassemia was tested and assimilated into multiple figures (Figure. 2 to 6). 96% study subjects knew and understood that Thalassemia is a genetic disease passed on through generations while 4% did not understand the cause (Figure 2).

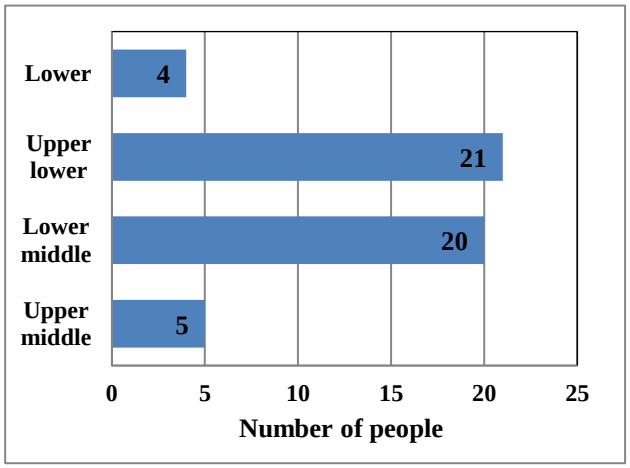

Figure 1: Socio-economic status of study subjects according to kuppuswamy socio-economic scale.

Table 1: Sociodemographic profile of study subjects.

Age (in years)	Male	Female	Total
21-30	14	4	18
31-40	15	5	20
41-50	5	1	6
51-60	4	2	6
Total	38	12	50
Education			
Post-graduate	3	0	3
Graduate	6	0	6
High school	7	1	8
Middle school	3	0	3
Primary school	8	4	12
Illiterate	11	7	18
Total	38	12	50
Occupation			
Professional	2	0	2
Shop owner/clerical/farmer	11	0	11
Skilled	14	0	14
Unskilled	11	0	11
Unemployed	0	12	12
Total	38	12	50

When asked about the family history of Thalassemia, only 20% subjects reported Thalassemia in one or the other relative while 10% reported the disease in siblings of the patient being transfused. In 10%, history of disease was positive in a relative as well as a sibling while no family history was present in 82% (Figure. 3). Only 6% subjects responded positively to the history of consanguineous marriages in their family over the generations (Figure 4). 96% subjects considered this disease to be a source of financial burden to the family (Figure 5) and 94% considered this as a cause of emotional distress in the family (Figure 6).

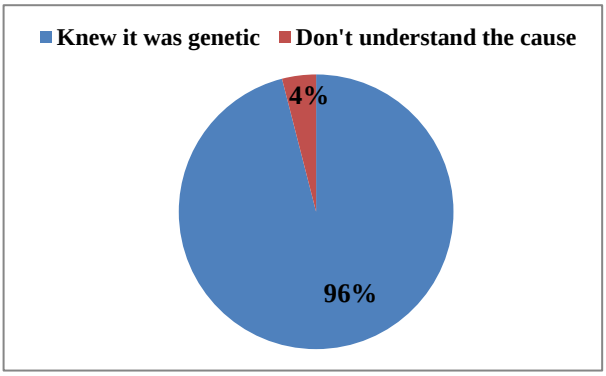

Figure 2: Knowledge about the cause of thalassemia.

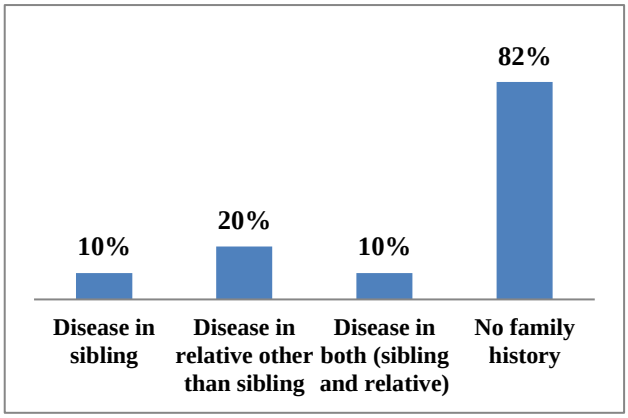

Figure 3: Family history of thalassemia (multiple responses).

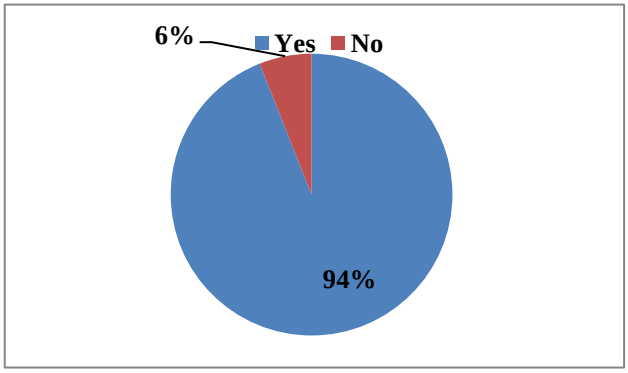

Figure 4: History of consanguineous marriages in the family.

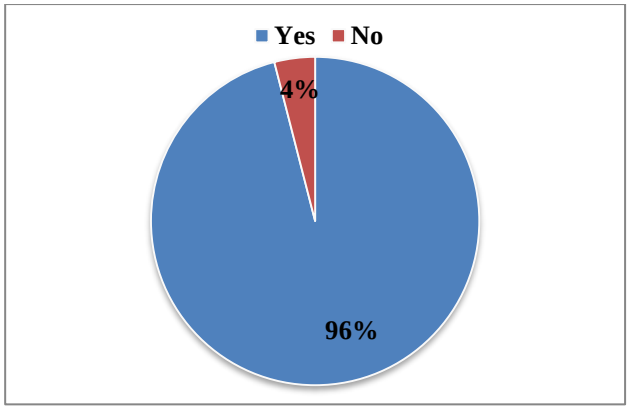

Figure 5: Thalassemia as a financial burden for the family.

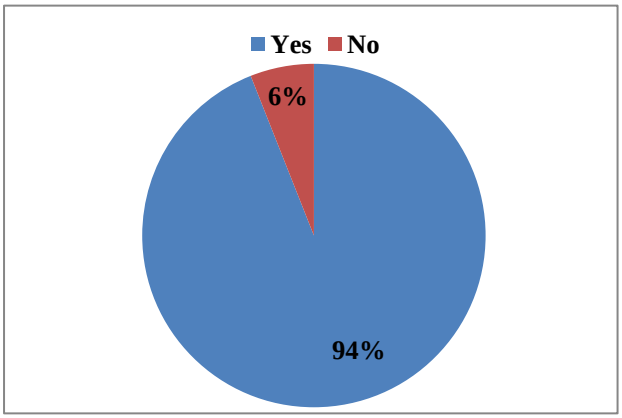

Figure 6: Thalassemia as a cause of emotional distress in the family.

When testing the knowledge of the subjects regarding management and treatment of Thalassemia, 100% subjects knew that blood transfusion is the primary form of management, 100% knew that bone marrow transplantation is the sole treatment available and 100% knew about the indications of splenectomy in Thalassemia patients. When testing the knowledge about complications of chronic blood transfusions, 100% knew that there could be reactions to the blood being transfused and that iron overload could be a potential complication of repeated transfusions. 100% subjects knew that iron chelation therapy is the only prevention and treatment of iron overload that may happen due to chronic transfusions (Table 2).

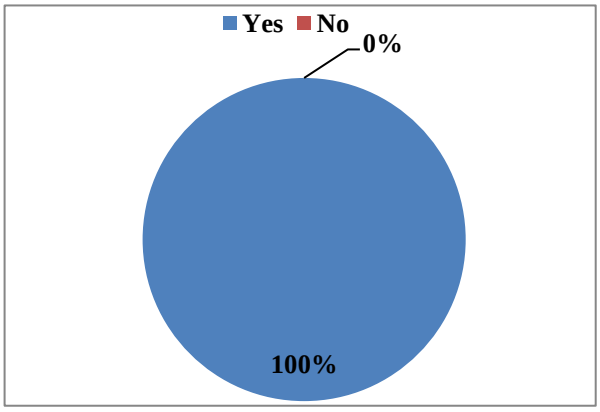

Figure 7: Knowledge about the need of Hepatitis B vaccination in chronic transfusion patients.

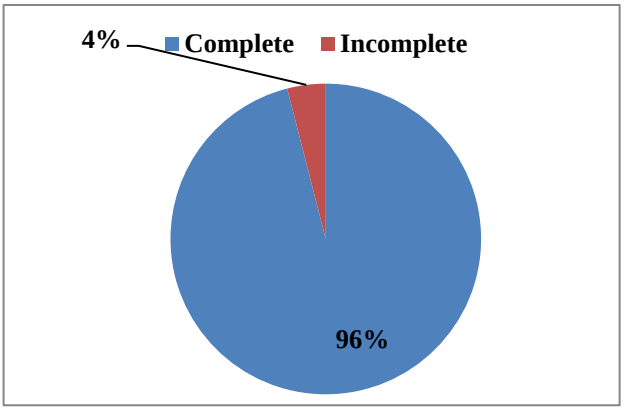

Figure 8: Hepatitis B vaccination administered.

When testing the attitude and practice of subjects towards prevention of Thalassemia, 100% subjects were aware of the importance of premarital counseling and antenatal testing but only 6% subjects got antenatal screening done for their subsequent child. Furthermore, only 2% subjects reported advising premarital counseling in their known groups of family, friends and neighbors and only 12% reported advising antenatal screening to pregnant women they knew while no one (0%) reported advising their known people against consanguineous marriages as a form of prevention (Table 3).

Table 2: Knowledge regarding management and treatment of Thalassemia.

	Knowledge of blood transfusion as the primary management	Knowledge of bone marrow transplantation as the sole treatment	Knowledge of indications of splenectomy specific to thalassemia	Knowledge of reactions of blood transfusion	Knowledge of iron overload as a potential complication of blood transfusion	Knowledge of iron chelation as the prevention and treatment of iron overload
Aware	100%	100%	100%	100%	100%	100%
Not aware	0%	0%	0%	0%	0%	0%

Table 3: Attitude and practice in prevention of Thalassemia.

	Yes	No
Knowledge of importance of antenatal screening and pre-marital counseling	100%	0%
Did they screen their subsequent child before birth?	6%	94%
Did they advise their relatives, neighbors and/or friends against consanguineous marriage?	0%	100%
Did they advise premarital counseling in their known groups?	2%	98%
Did they advise antenatal testing for Thalassemia in pregnant women known to them?	12%	88%

When asked about the knowledge of importance of hepatitis B vaccination in patients requiring regular blood transfusions, 100% subjects knew that hepatitis B can be transmitted via infected blood during transfusion and that it can be prevented by complete hepatitis B vaccination. Out of the 50 subjects, 96% had gotten their child vaccinated against hepatitis B completely while 4% had gotten incomplete vaccination for their child (Figure 7, 8).

DISCUSSION

This observational hospital-based study interviewed either parent of 50 children aged 1 year to 22 years with a mean age of 9.62 years suffering with beta-Thalassemia major who visited the Thalassemia day care unit in Government medical college, Amritsar for regular check-up and blood transfusion between 1st July and 21st July 2019. Parents were interviewed in the language best understood by them. Majority of parents belonged to the upper lower (42%) and lower middle (40%) socioeconomic strata. Majority of the parents were either illiterate (36%) or had only primary schooling (24%). In the current study, we had a slight male preponderance of Thalassemia with 27 males comprising 54% and 23 females i.e. 46%. Thalassemia is an inherited autosomal recessive disorder, seen equally in males and females.[4] A study by Saxena A et al, and Goyal JP et al, showed a male preponderance similar to in this study.[5,10] However, the study conducted in Pakistan by Arif F showed a slight female preponderance.[11] In this study, 96% study subjects knew and understood the genetic nature of Thalassemia, including the fact that consanguineous marriages are a risk factor, while 4% did not understand the cause. This knowledge was better than that in the studies conducted by Biswas B et al, (47.6%), Saxena A et al, (47.5%), Arif F et al, (82%), Maheen H et al, (55.2%) and Basu M (60.05%).[3,5,11,12]

When questioned about their knowledge regarding management and treatment of Thalassemia, 100% subjects knew about blood transfusion being the primary management, 100% knew about bone marrow transplantation being the sole treatment available and 100% knew about the indications of splenectomy in Thalassemia patients. These results were better than that in the studies conducted by Biswas B et al, where only 75.9% knew about the importance of blood transfusion and by Saxena A et al, where only 62.5% knew.[3,5] Only 19.2% subjects knew about splenectomy as a treatment option in Biswas B3 et al, study which is way less than this study. Knowledge about bone marrow transplantation was only 2.7% in the study by Biswas B et al, 45.7% in Inamdar et al, and 60% in Ali et al.[3,14,15]

When testing the knowledge about the complications of chronic blood transfusions, 100% knew about the reactions to the blood being transfused and that iron overload could be a potential complication of repeated transfusions. 100% subjects knew that iron chelation therapy is needed for the treatment of the latter. In the study by Goyal JP et al, only two-third knew about the reactions to transfusion while most of them knew about iron overload which is a similar finding to this study.[10] 100% subjects knew the importance of hepatitis B vaccination in chronic transfusion patients. 96% had gotten their child complete hepatitis B vaccination while 4% had gotten incomplete vaccination for their child. Only 42% were completely immunized against hepatitis B in the study by Goyal JP et al, which is less than this study results.[10]

In this study, 100% subjects were aware of the importance of premarital counseling and antenatal testing but only 6% subjects got antenatal screening done for their subsequent child. Only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively in the study by Biswas B et al, 31.4% and 45.0% respectively in the study by Inamdar et aland 84.3% and 76.5% respectively in the study by Ishaq et al, 92.06% subjects were in favor of prenatal diagnosis but only 4.9% got prenatal diagnosis done during pregnancy in the study by Basu M, which is similar to the results in this study.[3,13,14,16] 60% knew the importance of screening but only 27.5% underwent screening for the next pregnancy in the study by Saxena A et al, former result being worse and latter result being better than this study.[5]

Furthermore, only 2% subjects reported to have advised premarital counseling in their known groups of family, friends and neighbors and only 12% reported to have advised antenatal screening to pregnant women they knew while no one (0%) reported to have advised their known people against consanguineous marriages as a form of prevention. Similar reporting could not be found in any literature to the best of our knowledge, but these

results suggest poor practice towards prevention of Thalassemia.

Valid conclusion can be drawn from this if further studies are done in this direction. 96% subjects considered this disease to be a source of financial burden to the family and 94% considered this as a cause of emotional distress in the family. In the study by Saxena A et al, 72.5% did not consider them as a burden even though 65% felt that there was a lot of family expenditure on that child and almost 62.5% of parents felt that they had an emotional turmoil in raising their child.[5] These results, although different in percentage, suggest that there are financial as well as emotional disturbances in the household due to this disease.

From this study, it was found that irrespective of age, education, occupation, income and socio-economic status, knowledge of the parents regarding the cause, course, management, treatment, major complications of management and treatment, and prevention of Thalassemia is adequate. This is due to the efforts of the social worker/counselor attached with the Thalassemia day care center and the Thalassemia society of Amritsar, Punjab, India. The social worker/counselor has spent sufficient time with each family to make them aware of every aspect of this disease. This emphasizes the need for such a social worker/counselor to be associated with every Thalassemia day care center so that awareness can be created regarding this disease in the people who will need it throughout their life and so that all the doubts and false beliefs of the parents are handled correctly.

Despite adequate knowledge regarding every aspect of this disease, there is a lack of attitude of 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 state funding towards prenatal diagnosis and the lack of availability of these tests in the local hospitals. Furthermore, individual money is spent by the parents for the leucocyte filters and iron chelation therapy needed for regular management of this disease which has made it a financial burden to the families. This suggests that government sponsorship is needed to put their knowledge into practice to prevent the birth of thalassemic children and decrease the disease burden in the families as well as in our country.

Thalassemia is a chronic disease with difficult management and multiple complications. Dealing with these on a daily basis takes a toll on the mental health of every child living with Thalassemia. Furthermore, these children have a low life expectancy, a fact that they need to be one with. Here comes the role of a child psychologist being associated with every Thalassemia day care center to cater to these very important needs of these children, an aspect that is not taken into consideration while formulating policies about different aspects of Thalassemia.

CONCLUSION

The chronicity and complications of Thalassemia affect the quality of life of the patients and their families and cause physical, psychological and economic problems. Majority of the families either cannot afford bone marrow transplantation or cannot find a matched donor, so they exclusively depend on blood transfusions as the primary management option, which creates a burden not only on the health system but also on the affected families.

Hence, there is a need to promote an attitude of practice in prevention of the birth of thalassemic children as mere knowledge regarding the disease is not enough in the present scenario where the disease burden is increasing as is the financial and emotional burden on the families. Government sponsorship in the availability of leucocyte filters and iron chelation as well as in setting up prenatal diagnosis centers in the local hospitals can go a long way in improving the practice of existing knowledge in the families of thalassemic children.

In addition to that, we also emphasize the role of a social worker working closely with the families of these children to create awareness regarding every aspect of Thalassemia which can help in clearing out any doubts or misbeliefs that the parents might have regarding this disease which will further promote better management by increasing the treatment compliance. We also emphasize the importance of a child psychologist in Thalassemia day care centers to cater to the mental health of these children which is as important as their physical well-being.

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REFERENCES

1. Walker BR, Colledge NR, Ralston SH, Penman ID. Davidson's Principles and Practice of Medicine. 22nd Ed. China: Elsevier;2014:1034.
2. Paul VK, Bagga A. Ghai Essential Paediatrics. 8th Ed. New Delhi: CBS Publishers and Distributors; 2014:341.
3. 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.
4. Thalassemia. 2019. Available at: https://en.wikipedia.org/wiki/Thalassemia#cite_ref-10. Accessed 2 July 2019.
5. 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.
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 Midwif Res. 2016;3(1)
7. Mendiratta SL, Mittal M, Naaz F, Singh S, Anand S. Role of thalassemia screening in prevention and control of thalassemia-a 5 year experience. Int J Reprod Contracept Obstet Gynecol. 2017;5(9):3107-11.
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 4 July 2019.
9. Colah RB, Gorakshakar A. Control of thalassemia in India. Thalassemia Report 2014;4:1955.
10. 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.
11. Arif F, Fayyaz J, Hamid A. Awareness among parents of children with thalassemia major. J Pak Med Assoc. 2008;58(11):621-4.
12. Maheen H, Malik F, Siddique B, Qidwai A. Assessing parental knowledge about thalassemia in a thalassemia center of Karachi, Pakistan. J Gene Counsel. 2015;24(6):945-51.
13. 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 Preven Medic Holistic Health. 2015;1(1):6-13.
14. Inamdar S, Inamdar M, Gangrade A. Stress level among caregivers of thalassemia patients. Community Med. 2015;6(4):579-8.
15. Ali S, Safiullah MF. Awareness of Parents Regarding Beta Thalassemia Major Disease. Khyber Med Univ J. 2015;7(2):72-5.
16. Ishaq F, Hasnain Abid FK, Akhtar A, Mahmood S. Awareness Among Parents of ββ-Thalassemia Major Patients, Regarding Prenatal Diagnosis and Premarital Screening. J Coll Physicians Surg Pakistan. 2012;22(4):218.

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