Innovare Academic Sciences

International Journal of Pharmacy and Pharmaceutical Sciences

ISSN- 0975-1491 Vol 7, Issue 9, 2015

Original Article

STUDY THE LEVEL OF AWARENESS AMONG SINDHI FAMILIES OF DURG, CHHATTISGARH (INDIA): A QUESTIONNAIRE BASED STATISTICAL STUDY

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Received: 19 Mar 2015 Revised and Accepted: 17 Jul 2015

ABSTRACT

Objective. The present study has been done with the following aims and objectives in mind: i) To determine the level of knowledge or awareness about Thalassemia among Sindhi families in Durg, Chhattisgarh regarding the cause and prevention of the disease and ii) graphically represents their status of awareness.

Methods. In this study, we have used a questionnaire method which is done among 12 Sindhi families and determined their response rate about Thalassemia. Data are collected by survey in Durg districts of Chhattisgarh that targeted Thalassemic Sindhi families, they are the members of Thalassemia Welfare Society (TWS), Raipur (Capital of Chhattisgarh)- it's an affiliated organization. We have examined the attitudes regarding management of Thalassemia disease (TD) through their responses against questionnaire and represented their responses using MATLAB 8.4.

Results. In our study, we have found that overall, 64.91% participants are females and 35.09% are males. Also 20% of respondents felt comfortable with the questionnaire method of TD. The frequencies of reactions were 20%, giving the right answers and 28%, giving wrong answers while half is not thinking about the given questionnaire.

Conclusions. We have obtained the knowledge level among Sindhi families is very poor about TD. Therefore variousprevention policies are must be organized to increase their knowledge about Thalassemia and improve Thalassemic children'ssurvival capability.

Keywords: Durg district of Chhattisgarh, Genetic disease burden, Knowledge about Thalassemia, Sindhi families, Thalassemia.

INTRODUCTON

Our genes are the directions for how our bodies function. We get 50% of our genes or qualities from our mothers and half from our fathers, making for two duplicates of each quality (gene) in our body. People with Thalassemia disease are conceived with it. It is not infectious, and you can't get Thalassemia disease from somebody who has it. It is in our genes. The main path for somebody to have Thalassemia illness is to have inherited one quality for their red platelets that is not living up to expectations from their mother, and one non-meeting expectation quality of their father. Individuals with Thalassemia disease have inherited two qualities that are not meeting expectations appropriately.

Thalassemia major is a severe form of Thalassemia in which patient needs lifetime blood transfusion and appropriate medication [1]. Thalassemia major patients are diagnosed on the premise of history and hemoglobin–Electrophoresis (it is a test to distinguish the sorts of hemoglobin chains in a single person. The chains are sorted by size and electrical charge utilizing differential relocation through a gel) with evaluation of HbF and HbA_2 by High-Performance Liquid Chromatography (HPLC). Since the frequency of Beta-Thalassemia among different groups is higher, it is roughly 3 to 17 percent in India [2-4]. According to the screened population of Chhattisgarh [5] Thalassemia trait in the screened population is approximately 10 percent where the frequency of the Thalassemia Gene (TG) is higher among Sindhi families. Treatments for Thalassemia major patients impose a budgetary trouble in the family.

Thalassemia disease requires a significant degree of medical involvement, and family members are one potential provider of care for patients who do not have access to experts. Therefore, it is required for the parents of Thalassemia children, to have adequate knowledge about Thalassemia management. The objective of this study is to focus the knowledge level of Thalassemia disease (TD) among Sindhi families at their homes in Chhattisgarh, a state spotted in the central part of India. In this study, we use a questionnaire method which is done among 12 Sindhi families and determined their knowledge level, attitudes and beliefs of the participants about TD.

The remaining part of this paper is organized as follows: The prevalence of genetic diseases is explained in Introduction section and the date of questionnaire method is shown in Materials and Methods section. A response rate of the questionnaire is graphically represented in Result section. Discussion about the responses of the questionnaire and interview are considered in Discussion section and the conclusion section gives an output of the study.

Prevalence of genetic diseases in Chhattisgarh between different communities

Thalassemia and other hemoglobin disorders like sickle cell hemoglobin [6] are reported to be common in central India, especially in Chhattisgarh and Madhya Pradesh. Sickle cell disease (SCD) is an autosomal dominant hemoglobinopathy. Chhattisgarh is the 26th state of India, which came into existence on 1st November 2000. Sickle cell infection (SCD) makes a rising well being issue in different population groups of Chhattisgarh. The associated fig. 1, shows to the spreading of sickle cell disorders, β-Thalassemia trait, and the glucose-6-phosphate dehydrogenase (G6PD) enzyme deficiency in four tribes of Chhattisgarh and Orissa [7] where Thalassemia and G6PD are the form of genetic disorders.

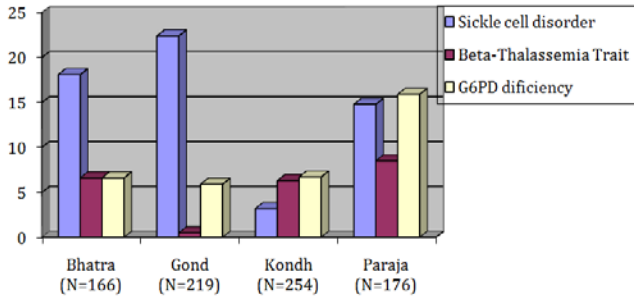

Fig. 1: Prevalence of SCD, Beta-Thalassemia trait and G6PD deficiency in Chhattisgarh, India

The prevalence of genetic diseases such as SCD, Beta-Thalassemia trait and G6PD deficiency in 815 screened populations was 3.2% to 22.5%, 0.5% to 8.5% and 6% to 16%, respectively, among the Bhatra, Gond, Kondh and Paraja tribes belonging to bordering districts of Chhattisgarh and Orissa.

Clearly, the prevalence rate is very high among this population. There is a need to generate effective prevention programs in Chhattisgarh to eradicate genetic diseases from the different ethnic group. The article in hand is designed with a view to present a status of Thalassemia disease in Chhattisgarh state.

Prevalence of thalassemia in chhattisgarh

Chhattisgarh is one of the developing states of India. As per enumeration 2011 its population in excess of 2.5 crore. Durg is one of the urban districts of Chhattisgarh, arranged on the east bank of a waterway Shivnath. It is proclaimed of Chhattisgarh's Mechanical Advancement, Social skill, Social amicability and significant utilization of assets.

The Sindhi is one of the biggest phonetic groups, moved around 65 years back from the Sind region of West Pakistan to India [8]. The frequency of Thalassemia among Sindhis is higher in India [9, 10].

Presently Thalassemia emerges as a physiological and monetary load in distinctive states of India, Chhattisgarh is one of them where an office for diagnosing Thalassemia is extremely poor. The following table 1 and fig. 2 are represents year-wise distribution of the Thalassemia gene in Chhattisgarh state:

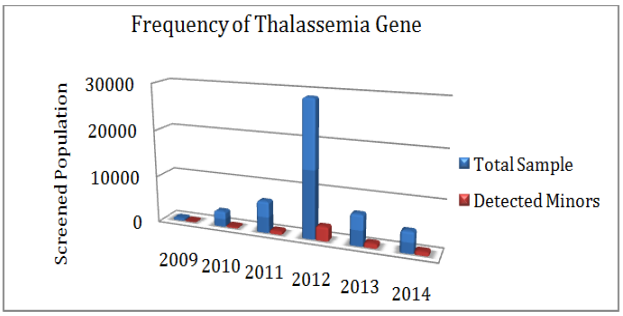

Fig. 2: Year-wise distribution of thalassemia gene in chhattisgarh, India

Chhattisgarh is one of the creating states of India where state level population based screening for Thalassemia yet not done. Above information show that in 2012 transporter recurrence is acquired that 10.61% of screened population and in 2013 it is figured as 14.65% and finally in 2014 it is turned into 17.95%. Accordingly, we watch that Thalassemia carrier frequencies are expanding year by year in Chhattisgarh. There is fundamental in Chhattisgarh each Thalassemia focus ought to have a pediatrician or a grown-up cardiologist with information of overseeing cardiovascular intricacies in Thalassemia patients. Also, if we focus on Thalassemia treatment costs, then the following table 2 shows the approximate cost related to their treatment:

Table 1: Year-wise distribution of thalassemia trait in chhattisgarh state of India

Years	Total Samples (N)	Detected Minors	Minors in Percent
2009	497	60	12.07%
2010	3,342	317	9.48%
2011	6,758	760	11.24%
2012	28,911	3,055	10.57%
2013	6,620	970	14.65%
2014	4,523	812	18.95%
Total	50,651	5,974	11.79%

Table 2: Available treatments and related costs of thalassemia major

Type of treatments	Approximate-Cost/Patient (Cost in Indian currency)
Regular blood transfusions	56200/-for 18 B/Ts
Medications (to decrease amount of iron in the body, called chelation therapy)	48000/-to 144000/-Depends upon Body Weight
Surgical removal of the spleen (if necessary)	32000/-+antibiotics 18000/-yearly
Daily doses of folic acid supplements Monitoring of the gallbladder, liver, and bone density	520/-, 24000–36000/-
Bone marrow Transplant	1000000 to 2000000/-
Other Medications to maintain the complications generated by Iron overload	24000/-
Food supplements with no Iron	18000/-
Transportation Cost	24000/-
Hepatitis B, C & HIV Treatment	33000/-,+500000/-–600000/-,+48000/-= 581000/-to 681000/-

- The cost may vary from hospital to hospital.
- Endocrinology complications (delayed puberty, diabetes, etc.) = 460000/-to 632000/-.
- The above cost is to treat the physical complications only. The socio-psychological problems and financial burden faced daily by the child & parents can`t be calculated.
- In Chhattisgarh Thalassemia Carrier frequency is higher among Sindhi families; it varies 10% to 12% (approximately).
- In Chhattisgarh approximately 500 to 600 patients suffering from Thalassemia major.

The data shown in table 1 and table 2 are sourced by the Thalassemia Welfare Society, Bhilai, Chhattisgarh. According to table 2, the cost of Thalassemia treatments varies from thousand to lack per year, depending upon the kind of treatment opted by the parents of a patient. Thalassemia is a preventable infection. It mainly requires a heightened awareness and sensitivity on this subject. For the risk prediction of Thalassemia [11-13] in a person see fig. 3, according to which an individual ought to be proposed for Thalassemia carrier testing if he/she is belonged to the following category:

Therefore, two people with Thalassemia trait should be not married to each other because in this case, there is a 25 % risk probability of the birth of Thalassemia major children. Furthermore, a survey conducted in England, among population of South Asian descent in 1995 found that only 25% were aware of Thalassemia. After a 3-year awareness campaign via various platforms, the awareness, increased to 60% in 2000. Similarly the percentage of reported blood screening increased from 4% to 10% after this campaign [14]. This

shows that prevention programs are effective, even their compensation are previously seemed in different countries like Cyprus, Sardinia and Italy.

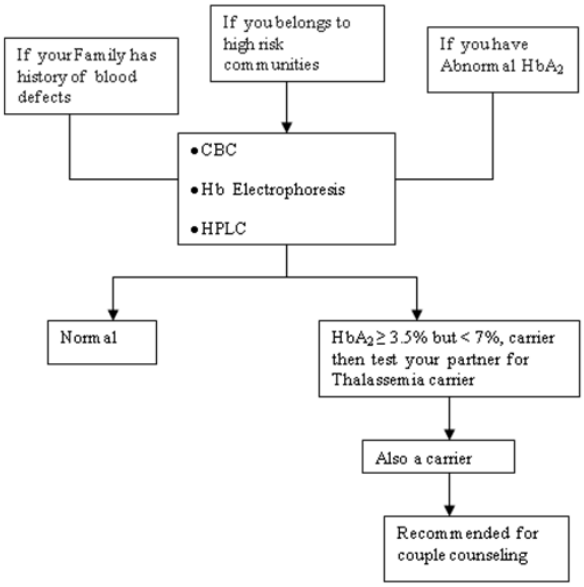

Fig. 3: Flow chart for the identification of thalassemia carrier

Prevalence of thalassemia among sindhi community

Durg is one of the growing districts of Chhattisgarh. According to the Thalassemia screening programs see fig. 2, the prevalence rate of Thalassemia gene is high among Sindhi communities. Therefore the present study focuses on their knowledge level of Thalassemia among Sindhi families of Durg. There are approximately 145 registered Thalassemia patients in TWS, Raipur (Chhattisgarh), many of them are Sindhies.

They have a higher frequency of Thalassemia gene that is approximately 10 percent. Also the parents of the Thalassemic children have inadequate income to arrange the better resources for treatment. In Chhattisgarh state the prevalence of Thalassemia gene is an initial stage. This paper is helpful to create awareness about Thalassemia among Sindhi community also it has increased the quality of care for Thalassemia patient and increases their survival capability.

MATERIALS AND METHODS

This survey based on the questionnaire was approved by the Thalassemia Welfare Society (TWS), Bhilai. The patients are registered in TWS, Raipur the capital of Chhattisgarh. Now a day it is an increasing global health burden in Chhattisgarh. Relatively large numbers of the population have Thalassemia trait. Since Sindhi in this study, we targeted some Sindhi family's lives in Durg District of Chhattisgarh. About 57 people (37-Females and 20-Males) were surveyed in their homes on 07 June 2014. The questionnaire and interview were mainly consisted of sixteen questions, relating to the following things: basic knowledge about Thalassemia, treatments of Thalassemia, family planning, burden facing by family and the management of Thalassemia. The study sample from different families with Thalassemia children was collected randomly. All the participants filled out a questionnaire and after the completion of questionnaire next session we interact with Thalassemia children's parents to know their personal experience during the treatment of their children. Through this study, we create the knowledge level about Thalassemia among the Sindhi families. The following table 3 shows the demographic characteristics of respondents were total number of participants (**N**) are 57 and table 4, shows their responses against questionnaire about Thalassemia disease.

Table 3: Demographic characteristics of respondents (N= 57)

Socio-demographic variable	Total N=57	Percent (%)
Gender		
Male	20	35.09
Female	37	64.91
Community		
Sindhi	53	92.98
Others	04	7.02
Age		
<20	27	47.37
21-40	19	33.33
41-50	06	10.53
50-60	03	5.26
>60	02	3.50
Educational Level		
Lower Education	05	8.77
Primary School	10	17.54
Secondary School	23	40.35
University	19	33.33
Main Occupation		
Unemployed	07	12.28
Job in private company	05	8.77
Self Business	15	26.31
Housewife's	11	19.30
Students	19	33.33
Marital Status		
Single	04	7.02
Married	22	38.60
Not Married	31	54.38
Average monthly household income in 12 families		
<10,000	01	1.75
10,001-20,000	08	14.03
>20,001	03	5.26
Locality		
Urban	54	94.74
Rural	03	5.26

Table 4: Generates the frequency of responses for Q. 1 to Q.16

S. No.	List of Questions	Answer (N=57)		
		Correct (X) (%)	Don't know (Y)(%)	Wrong (Z)(%)
1.	Can Thalassemia disease affect the red blood cells?	07(12.28)	19(33.33)	31(54.39)
2.	Is Mediterranean countries are at a higher risk of being genetic carriers of Thalassemia disease?	02(3.51)	47(82.46)	08(14.03)
3.	If it's possible that only one parent is a carrier of a Thalassemia trait, there is no chance of having a baby with Thalassemia disease?	05(8.77)	08(14.03)	44(77.19)
4.	Is Thalassemia carrier is not a disease?	20(35.09)	34(59.65)	03(5.26)
General Awareness				
5.	Is Thalassemia an infective disease?	22(38.60)	17(29.82)	18(31.58)
6.	A couple have Thalassemia trait, is there a chance their child will have Thalassemia?	13(22.81)	35(61.40)	09(15.79)
7.	Is Thalassemia due to our diet?	09(15.79)	37(64.91)	11(19.30)
8.	Is Thalassemia due to an allergic reaction?	08(14.03)	35(61.40)	14(24.56)
Diagnosis				
9.	Can Thalassemia be detected by a blood test?	12(21.05)	17(29.82)	28(49.12)
10.	Can Thalassemia be detected by an HPLC test?	08(14.03)	22(38.60)	27(47.37)
Treatment				
11.	Can Thalassemia major treated with blood transfusions?	26(45.61)	15(26.31)	16(28.07)
12.	Can Thalassemia major treated by with surgery and medications?	08(14.03)	34(59.65)	15(26.31)
Prognosis				
13.	Will a person who has been diagnosed with Thalassemia trait always be a carrier?	12(21.05)	37(64.91)	08(14.03)
14.	If a person has the Thalassemia trait, will he/she lookHealthy and show no symptoms of being affected?	12(21.05)	39(68.42)	06(10.53)
15.	Can individuals with Thalassemia lead normal lives with appropriate treatment?	14(24.56)	33(57.89)	10(17.54)
16.	BMT is the available option for the control of Thalassemia?	13(22.81)	28(49.12)	16(28.07)
	Total	20.94	50.11	28.95

RESULTS

In our study, we have found that overall, 64.91% participants are females and 35.09% are males. Also, 20% of respondents felt comfortable with the questionnaire method of Thalassemia disease. The frequencies of responses were 20%, giving the right answers and 28%, giving wrong answers while half is not thinking about the given questionnaire.

We have obtained the knowledge level about Thalassemia disease among Sindhi families are very poor. Therefore, various prevention policies are must be organized to increase their knowledge about Thalassemia management and improve Thalassemic survival capability.

The following bar chart represents the response of the questionnaire and interview:

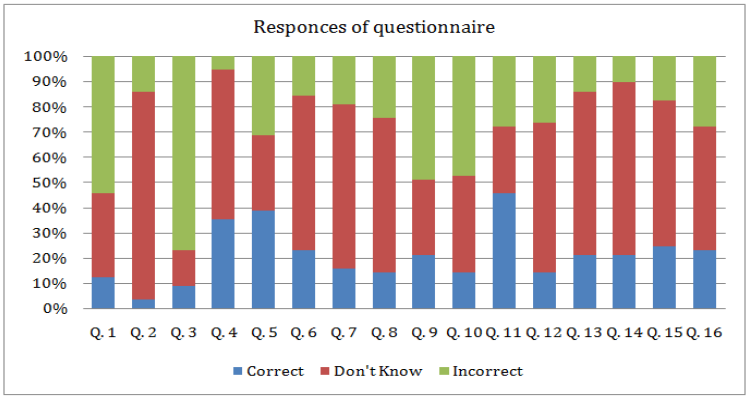

Fig. 4: Responses of questionnaire and interview

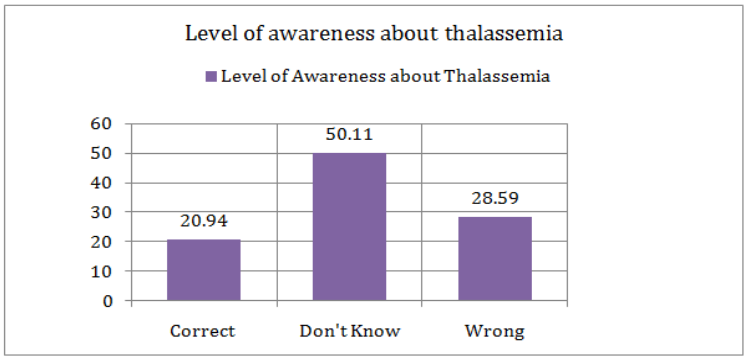

Fig. 5: Frequency of knowledge about Thalassemia of the participants

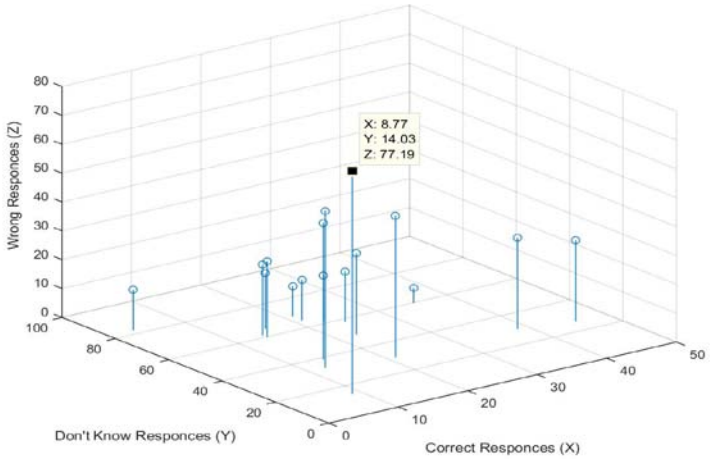

Fig. 6: Frequencies of responses of participants in 3D view

The resultant fig. 4, fig. 5 and fig. 6 are represent response rate of the questionnaire where output field refers to the presence and absence of awareness level about Thalassemia disease among the participants. Clearly, fig. 4 shows the responses of questionnaire on column chart, of the taking an interest families, 64.91% were females and 35.09% were male. The fig. 5 states to the frequencies of reactions were 20%, giving the right answers and 28%, giving wrong answers while half is not thinking about the given questionnaire. Also fig. 6 shows the frequencies of each questionnaire in one view and state about the responses of participants, this depicts the data given in table 2. For example, the value of correct response (X), Don't know response (Y) and Wrong response (Z) are 8.77, 14.03 and 77.19 respectively can be verified with S. N. 3 of table 2.

DISCUSSION

In Chhattisgarh, Thalassemia Carrier frequency is higher (approximetly 10%-12%) among Sindhi families. Awareness level among this community shows their thalassemic childrens survival capability. In this study the results illustrate that the level of awareness among Sindhi families is inadequate. Accordingly, we acquired that the source to increase the knowledge about Thalassemia is lacking, which is straightforwardly influencing the treatment and standard consideration of their Thalassemia adolescents. Since the cost of Thalassemia treatment is expensive in this manner personal satisfaction of Thalassemia patient relies on upon their family income. As indicated by the overview information families are status, they are not proficient to give better treatment. Basically the affected children from low income families do not reach at the age forty since lack of facility and less knowledge about the management of Thalassemia. Psychological complications in patients with Thalassemia are common. These ranges of inappropriate coping strategies reduced health-related quality of life as a result of negative mood, and daily activity and role limitations, to neurocognitive impairment. Hematologists need to learn more about the manner in which Thalassemia patients adapt to their condition. This can be achieved through increasing parent's knowledge about medical treatment that assesses psychosocial experience, and the continuing effects of both medical and psychological therapies. In the absence of a sufficient knowledge about Thalassemia cure, it is recommended that psychological interventions should be incorporated into protocols for the management of patients with Thalassemia and offered as standard care to help improve their general quality of life.

CONCLUSION

The level of knowledge about Thalassemia between Sindhi families is inadequate. They need different resources through which they can give his children good quality of life. This survey also showed that Sindhi children are facing the physiological burden in Thalassemia. Most of the Thalassemic children's belong to middle class families, who do not afford the costly medicine for removing the excess of iron in the body. Treatments for Thalassemia major include regular, lifetime, transfusions of red blood cells associated with iron chelation therapy. Although repetitive transfusions are a palliative therapy, it enables patients to develop normally, improve their quality of life and reach adult age. All children should be started on a chelation program early in life to reduce iron from the body.

Also family members before making new wedding locks make sure that one of the partners should not carrier of the Major Thalassemia virus. Therefore, awareness is the key to prevent Thalassemia not only in Sindhi community this we can apply each and every community to stop transforming the deadly Thalassemia to our next Generations.

Limitations

There are certain limitations to this study. Because of the small sample size, the results obtained may not truly reflect awareness of Thalassemia in the Sindhi community. There is a possibility that some of the responses to certain questions being inaccurate, namely the question on the respondents' Thalassemia/Thalassemia trait status, as testing for Thalassemia is not routinely done in Chhattisgarh.

ACKNOWLEDGEMENT

The authors are grateful to Dr. Kiran Makhija (pediatrician) associated with Thalassemia Welfare Society, Bhilai and Mr Pramod Puri (General secretary of the Thalassemia Welfare Society, Bhilai, Chhattisgarh) for their support. Also, special thanks to parents of Thalassemia children for their support and cooperation. The authors are also thankful to the patient who are fully supported to us and share their personal experience about this dangerous disease.

CONFLICT OF INTERESTS

The authors would like to thank the Thalassemia Welfare Societies of Chhattisgarh for their support. The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

REFERENCES

1. Thakur S, Sharma R. Prevention measures for thalassemia in chhattisgarh, India: with the help of mathematical models. Am J Maths Math Sci 2013;2:193-200.
2. Balgir RS. The genetic burden of haemoglobinopathies with special reference to community health in india and the challenges ahead. Indian J Hematol Blood Transfusion 2002;20:2-7.
3. Grow K, Vashist M, Abrol P, Sharma S, Yadav R. Beta thalassemia in india: current status and the challenges ahead. Int J Pharm Pharm Sci 2014;6:28-33.
4. Rakholia R, Chaturvedi P. Prevalence of β-Thalassemia carrier state in Sindhi community of Wardha and evaluation of risk

factors for β-Thalassemia trait. Nigerian J Clin Prac 2013;16:375-80.

5. Thakur S, Sharma R, Raw SN. Incidence of thalassemia and sickle cell disease in chhattisgarh, Central ndia: using hardy-weinberg equations. J Mol Genet Med 2015;9:155.
6. Paunipagar PV, Patil SKB, Singh CM, Arya RC. Sickle cell gene in trible area of rajnandgaon districts of chhattisgarh. Indian J Prev Soc Med 2006;37:143-7.
7. Balgir RS. Genetic disease burden, Nutrition and determinants of tribal health care in chhattisgarh state of central-east india: a status paper. Online J Helt Appl Sci 2011;10:1-7.
8. Das K, Dhas P, Sahu PN, Rao VR, Mohanty D. Abnormal hemoglobins (HbD and HbQ India) and β-Thalassaemia among the Indian Sindhis. Hered Gen; 2013.
9. Sukumaran PK. Abnormal Hemoglobins in India. In: Trends in Haematology. School of Tropi Med; 1975.
10. Agarwal MB, Varandani DG, Joshi RH, Bhargava AB, Mehta BC. Haemoglobin D disorders in 13 unrelated families. Indian J Med Res 1981;73:554-7.
11. El-Hazmi MAF. Care for people with haemoglobin disorders. World Heath Forum 1994;15:165-8.
12. Ahmadnezhad E, Sepehrvand N, Jahani FF, Hatami S, Kargar C, Mirmohammadkhani M, *et al*. Evaluation and cost analysis of national health policy of thalassaemia screening in west-azerbaijan province of iran. Int J Prev Med 2012;3:687–92.
13. Colah RB, Gorakshakar AC, Nadkarni AH. Invasive and non-invasive approaches for prenatal diagnosis of haemoglobinopathies: experiences from India. Indian J Med Res 2011;134:552-60.
14. Kukreja A, Khan A, Xian L, Razley Rahim Z. Awareness of thalassemia among rural folks in penang, Malaysia. Int J Health 2009;12:1.