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RESEARCH ARTICLE

PERCEPTION OF Hb E PROBANDS–A STUDY AMONG GARO TRIBES IN TURA TOWN, MEGHALAYA

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ABSTRACT

The present study is an attempt to understand the awareness about Hb E among the affected people and their family members of Tura town. The study reveal that ignorance and unawareness about the prevalent hereditary haemolytic disorders in these vulnerable communities of Meghalaya, which is affecting the normal life of these tribes. The defenceless peoples are not aware about its health implications, their mode of transmission and available testing facilities.

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INTRODUCTION

More than 1000 naturally occurring human haemoglobin variants with single amino acid mutations throughout the molecule have been identified (Christopher *et al*., 2013). The most common and medically important Hb variants include HbS, Hb C, Hb E and various thalassemias. All of which are under positive genetic selection because they confer survival advantages in areas where malaria is endemic (Weatherall and Clegg 2001). Haemoglobin E is one of the world's most common abnormal haemoglobin mutations in Southeast Asians including India. It is an inherited autosomal recessive disorder. The occurrence of Hb E is most concentrated at the border of Thailand. It is estimated that 30 million Southeast Asians are heterozygous for Hb E and one million are homozygous (Weatherall *et al*., 2010). The substitution of lysine for glutamic acid at position 26 of the β-globin chain is a characteristic of Hb E. It results in a heterogeneous group of disorders whose phenotype ranges from asymptomatic to severe. It is characterized by abnormally small red blood cells which generally causes no health problems. Some people may suffer mild haemolytic anaemia or slightly enlarged spleen. Signs and symptoms of haemoglobin E disease may vary on an individual basis for each patient.

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Occasionally one may inherit thalassemia gene from one parent, and structural Hb gene from the other, resulting in compound heterozygote e.g.HbS/ βThal, HbE/ βThal or Hb S/E. For proper management differentiating the Hb E types is very important because the medical conditions for each type vary considerably.

These red cell inherited diseases are cause of public health concern and also a genetic burden due to high level of morbidity, mortality and foetal loss in backward, under privileged, and vulnerable people. There are reports proving the fact that Hb E carrier and βThal/Hb E mothers in their reproductive life either had spontaneous abortions or neonatal deaths (Balgir, 2014).

Garos are indigenous people of Meghalaya. They are one of the few matrilineal societies in the world. They mostly prefer to encourage endogamy (marriage within one's own tribe or group as required by their custom or law) and consanguineous marriages in their society .There are limited studies about haemoglobin E among mongoloid tribes. Garo tribes being mongoloids (Das M, 1993) and they also come under the HbE trait affected people. They have been living in this region from time immemorial under similar environmental conditions showing affinity both in culture and biology.

MATERIALS AND METHODS

The present study has been conducted in Tura town, West Garo Hills of Meghalaya, India. It is located at the foot hills of Garo Hills. It is the district capital of West Garo Hills. The four major hospitals in the Tura town were covered as a part of survey regarding Hb E status among Garos in the Tura town. Doctors of the respective hospitals were approached to know the exact condition of Hb E in the Tura town and the researcher tried to look for people who have come for various check-up, to find if any Hb E affected person has approached the doctor. All the hospitals of Tura town were consulted to get the names of probandsdiagnosed with Hb E type, but we could not get any information about the disease. Therefore, the snow ball sampling method was used to find out the persons diagnosed with Hb E type in the study area. Finally we selected fifty people those who were suffering from this disorder. They were approached with appropriate schedule containing relevant questions prepared by the researcher according to the objectives and variables. These fifty people (proband) were considered as the sample size in the present study .The study was conducted for time period of seven months from September, 2014 to April, 2015.The data was entered into SPSS version 17 to compute descriptive data. As a first step, a frequency analysis was undertaken on the primary data. Cross variable tabulation was used to analyse and interpret the relationships between variables applied on the nominal questions. The Chi-square test has been used to test the association between two variables for nominal scale questions. Mean and standard deviation were also used to work out the average of the responses. The Cramer test has been used to find the effects of one variable (independent variable) on the other (dependent variable).

RESULTS AND DISCUSSION

Fifty probands were considered as sample size for the analysis. Majority of probands are females belonging to age group of above 16 years. The selected female probands belong to the group of Hb E trait and disease. All the probands reported of having non-consanguineous relationship with their spouses. Socio-psychological parameters like foetal loss, Hb E affected family members of probands across Hb E type, quality of life, deprivation, encouraging family members, social awareness, genetical awareness were taken into account. Foetal loss has been taken into consideration as there were reports that Hb E/βThal or Hb E carrier mothers in their reproductive life either had spontaneous abortions and neonatal deaths (Balgir.R.S, 2014)

Table 1 explains foetal loss among married Hb E type probands. In case of married Hb E type probands 86%foetal mortality has not taken place but 8% and 6% of them reported one foetal loss and two foetal losses respectively. Haemoglobin E type wise analysis revealed equal number (12) of foetal mortality in “one foetal loss” and “two foetal loss” category among Hb E trait probands. It was followed by Hb E disease respondents with “one foetal loss”. As a whole it may be inferred that, even though foetal mortality was not significant, among trait probands noticeable foetal loss was inferred.

Table 1. Foetal loss –Based on Hb E type of the married Probands

Foetal loss		HbE type			Total
		Trait	Disease	Hb E/βThal	
0.00	Count	12	12	0	24
	% within foetal loss	50%	50%	0.0%	100.0%
	% within HbE type	76.0%	93.8%	0.0%	86.0%
1.00	Count	3	1	0	4
	% within foetal loss	75.0%	25.0%	0.0%	100.0%
	% within HbE type	12.0%	6.3%	0.0%	8.0%
2.00	Count	3	0	0	3
	% within foetal loss	100.0%	0.0%	0.0%	100.0%
	% within HbE type	12.0%	0.0%	0.0%	6.0%
Total	Count	18	13	0	31
	% within foetal loss	50.0%	32.0%	18.0%	100.0%
	% within HbE type	100.0%	100.0%	100.0%	100.0%

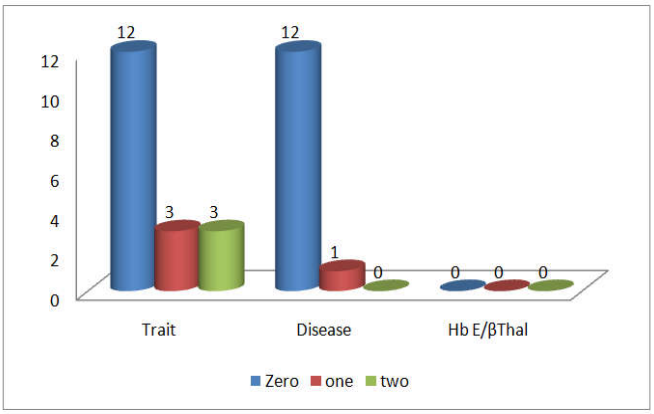

Fig. 1. Foetal loss –Based on Hb E type of the married Probands

Table 2. Hb E affected family members of probands across Hb E type

Effect of Hb E on family members		Hb E type			Total
		Trait	Disease	Hb E/βThal	
Parents	Count	3	1	1	5
	% within Hb E Effect on family members	60.0%	20.0%	20.0%	100.0%
	% within Hb E type	12.0%	6.3%	11.1%	10.0%
Spouse and children	Count	10	4	3	17
	% within Hb E Effect on family members	58.8%	23.5%	17.6%	100.0%
	% within Hb E type	40.0%	25.0%	33.3%	34.0%
Other family members	Count	1	3	4	8
	% within Hb E Effect on family members	12.5%	37.5%	50.0%	100.0%
	% within Hb E type	4.0%	18.8%	44.4%	16.0%
No idea	Count	11	8	1	20
	% within Hb E Effect on family members	55.0%	40.0%	5.0%	100.0%
	% within Hb E type	44.0%	50.0%	11.1%	40.0%
Total	Count	25	16	9	50
	% within Hb E Effect on family members	50.0%	32.0%	18.0%	100.0%
	% within Hb E type	100.0 %	100.0%	100.0%	100.0%

Table 2 reveals distribution Hb E affected family members of the probands across Hb E type. Irrespective of the Hb E type and who the family member is, it is seen that 60% were diagnosed with any of the Hb E whereas the rest 40% have never known about the importance of getting themselves diagnosed after the proband has been diagnosed (the reason they stated is that they have never had any symptoms for which they felt the requirement of consulting a doctor for diagnoses nor had any major health problems).

It is also analysed with respect to Hb E type of the probands, nearly 1/3rd (34%) of the probands ,got their spouse and children diagnosed with Hb E type followed by other family members (16%) and parents(10%).

Hb E type wise analysis reveals that in case of Hb E/β Thal nearly (44.4%) of their other family members were diagnosed followed by spouse and children (18.8%) and parents (11.1%). In case of trait, in more than 1/3rd (44%) probands none of their family members were diagnosed. Whereas 40% of them got their spouse and children diagnosed followed by parents (14%) and other family members (4%). Among the probands whose none of the family members were taken for diagnosis informed not having idea, in nearly 50% Hb E disease and 44% trait probands none of their family members were diagnosed. It was also reported that in case of proband diagnosed as trait their parents (60%) and spouse and children (58.8%) were diagnosed. Where as in case of disease (37.5%) and Hb E/β thalassemia ½ (50%) of them got their other family members diagnosed. As a whole it may be concluded that relatively many of the probands having either of the Hb E type their kith and kin were diagnosed.

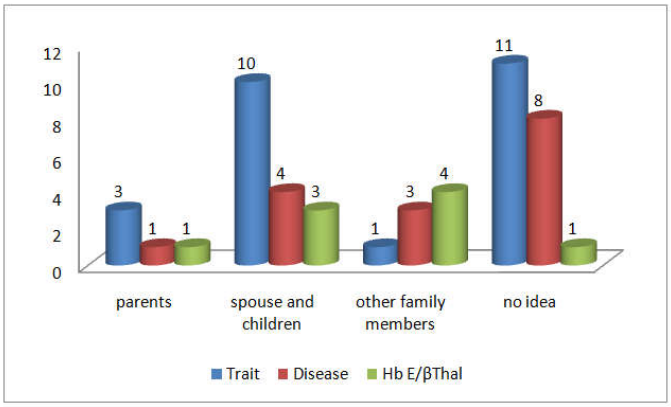

Fig. 2. Hb E affected family members of probands across Hb E type

In general every individual quality of life is explained from both their personal as well as their social life. In the context of Hb E type proband, personal life is understood to be active to lead beyond minimal normal life. For e.g.- if spouse proposes to go for shopping or to prepare some special food he or she should be in an active position to fulfil it. Similarly social life is expected to be visiting friends and entertaining friends and relatives, participating various religious and social functions. As regards with quality life is concerned among Hb E proband it was reported that relatively a very simple majority (52%) expressed that their quality of life as described above was not very encouraging whereas the remaining (48%) shared that they were attempting to have better quality of life to lead life like any other average being.

Table 3. Effect of Hb E type on quality of life

Hb E type		Effect on quality of life		Total	Chi-Square and P-Value
		Yes	No		
Trait	Count	7	18	25	Yeates correction value = 7.230 P =0 .027, df = 2 Cramer's V= 0.374
	Expected Count	11.0	14.0	25.0	
	H	28.0%	72.0%	100%	
	% of Total	14.0%	36.0%	50.0%	
Disease	Count	8	8	16	
	Expected Count	7.0	9.0	16.0	
	H	50.0%	50.0%	100.0%	
	% of Total	16.0%	16.0%	32.0%	
Hb E /βThal	Count	9	0	9	
	Expected Count	9.0	0.0	9.0	
	H	100.0%	0.0%	100.0%	
	% of Total	18.0%	0 %	18.0%	
Total	Count	22	28	50	
	Expected Count	22.0	28.0	50.0	
	% of Total	48.0%	52.0%	100.0%	

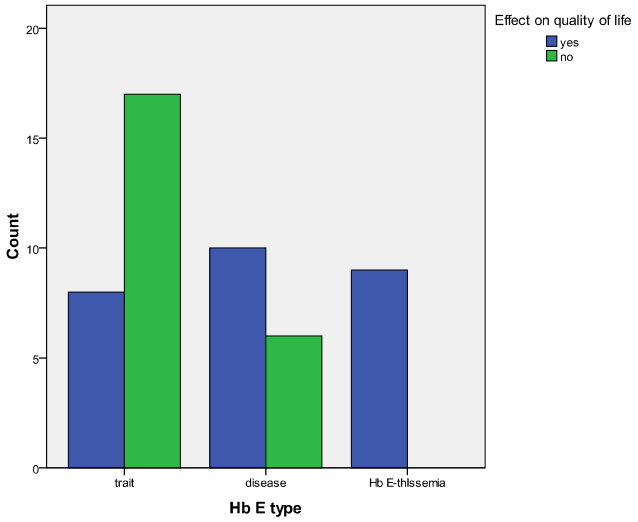

Fig. 3. Effect of Hb E type on quality of life

Hb E type wise analysis reflect that in case of Hb E disease probands equal number (50%) of them shared either of being positive or negative with regards to quality of life. In case of trait affected probands nearly ¾th of them (72%) expressed their displeasure on their quality of life and 100% of Hb E /βThal probands were positive about their personal and social life.

Table 4 explain sense of deprivation among probands. Sixty four per cent of the probands shared that they do not feel deprived of anything. Thirty Six per cent expressed that they definitely feel deprived of not gaining success as expected in their carrier like their counterparts. Cross variable analysis based on Hb E type explains that trait respondents were very

positive about getting expected things followed by diseased probands. None of the HbE /βThal respondents were optimistic about realisation of their aspirations. As a whole it may be stated that the majority of them are optimistic about their life and aspiration.

Table 4. Sense of deprivation undergone by the probands

Hb E type		Deprivation due to Hb E		Total	Chi-Square and P-Value
		Yes	No		
Trait	Count	3	22	25	Yeates Correction value = 25.826
	Expected Count	9.0	16.0	25.0	P = 0.000, df = 2
	H	12.0%	88.0%	100.0%	Cramer's V =0 .667
	% of Total	6.0%	44.0%	50.0%	
Disease	Count	6	10	16	
	Expected Count	5.8	10.2	16.0	
	H	37.5%	62.5%	100.0%	
	% of Total	12.0%	20.0%	32.0%	
Hb E/βThal	Count	9	0	9	
	Expected Count	3.2	5.8	9.0	
	H	100.0%	0.0%	100.0%	
	% of Total	18.0%	0.0%	18.0%	
Total	Count	18	32	50	
	% of Total	36.0%	64.0%	100.0%	

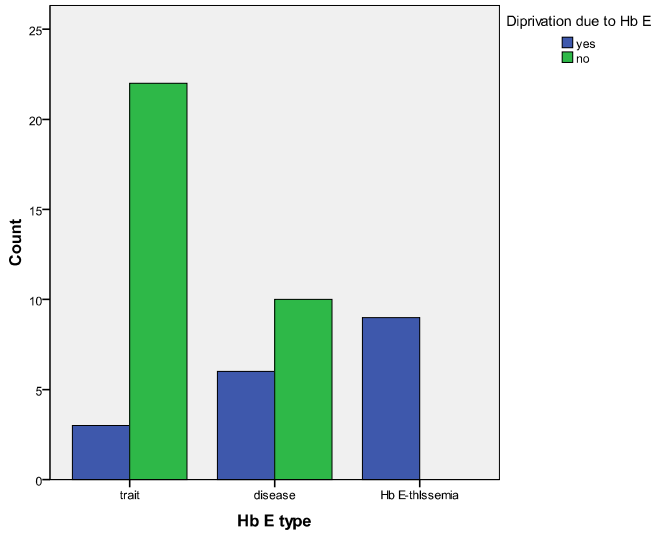

Fig. 4. Sense of deprivation undergone by the probands

The Chi-Square test for independence was used to find the relationship between probands Hb E type and Deprivation. The null hypothesis is "there is no association between probands Hb E type and Deprivation".

At significance level of 0.000 the Pearson Chi-Square value (Yeates Correction value) was 22.266 which reject the null hypothesis. In conclusion this can be said that there is an association between probands Hb E type and Deprivation. The Cramer's V value is 0.667 and it indicates that the effect of Hb E type on Deprivation is very strong.

It was enquired from the proband and his family members, if they were aware about Hb E are being a genetically inherited disease or not. Accordingly it was presented in the table 6.Most of (98%) of the proband were aware that they inherited the disease from their ancestors. This can be taken as positive sign towards understanding HbE, remaining 42% were ignorant of its roots of inheritance.

Table 5. Probands knowledge about Hb E type genetic inheritance

Genetic awareness on Hb E		Hb E type			Total
		Trait	disease	Hb E/βThal	
Yes	Count	16	10	3	29
	H	55.2%	34.5%	10.3%	100.0%
	V	64.0%	62.5%	33.3%	58.0%
No	Count	9	6	6	21
	H	42.9%	28.6%	28.6%	100.0%
	V	36.0%	37.5%	66.7%	42.0%
Total	Count	25	16	9	50
	Total	50.0%	32.0%	18.0%	100.0%
	% within Hb E type	100.0%	100.0%	100.0%	100.0%

Cross variable analysis based on Hb E type showed that 64% trait and 62% disease probands were aware of its genetic roots where as 66.7% of Hb E/ βThal patients stated that they were not aware of its genetic inheritance. It is to state that a simple majority of trait probands were aware of its roots that of other two types. As a whole it may be inferred that even though some awareness exists still much more effort is to be initiated by the respective institutions to make them aware to take preventive and corrective measures for defusing the Hb E from the society.

Table 6. Distribution of social awareness on Hb E across Hb E type

Society awareness on Hb E		Hb E type			Total
		Trait	disease	Hb E/βThal	
Yes	Count	0	0	1	1
	H	0.0%	0.0%	100.0%	100.0%
	V	0.0%	0.0%	11.1%	2.0%
No	Count	25	16	8	49
	H	51.0%	32.7%	16.3%	100.0%
	V	100.0%	100.0%	88.9%	98.0%
Total	Count	25	16	9	50
	Total	50.0%	32.0%	18.0%	100.0%
	% within Hb E type	100.0%	100.0%	100.0%	100.0%

H: horizontal, V: vertical

As a part of our inquiry we tried to find out about the awareness on Hb E in the society from the probands and accordingly it was presented in table 6. It is disheartening to state that 98% of the probands expressed that society at large were not aware of Hb E trait and its consequences where as only 2% stated that there is awareness among people with regard to Hb E.

Haemoglobin E type analysis reveals that in case of trait as well as disease proband expressed that there was no societal awareness, where as a very insignificant (11%) of Hb E/βThal.

probands stated that there is awareness among tribe. As a whole societal awareness regarding Hb E type health problems is very insignificant which is to be promoted very genuinely and rationally.

Table 7. Probands attempt to encourage family members for Hb E diagnosis-HB E wise

Hb E type		Encouraging family members for Hb E test			Chi-Square and P-Value
		Yes	no	Total	
Trait	Count	8	17	25	Yeates correction value = 0.611 P = 0.737, df = 2 Cramer's V = 0.111
	Expected Count	9.0	16.0	25.0	
	H	32.0%	68.0%	100.0%	
	% of Total	16.0%	34.0%	50.0%	
Disease	Count	7	9	16	
	Expected Count	5.8	10.2	16.0	
	H	43.8%	56.2%	100.0%	
	% of Total	14.0%	18.0%	32.0%	
Hb E/βThal	Count	3	6	9	
	Expected Count	3.2	5.8	9.0	
	H	33.3%	66.7%	100.0%	
	% of Total	6.0%	12.0%	18.0%	
Total	Count	18	32	50	
	% of Total	36.0%	64.0%	100.0%	

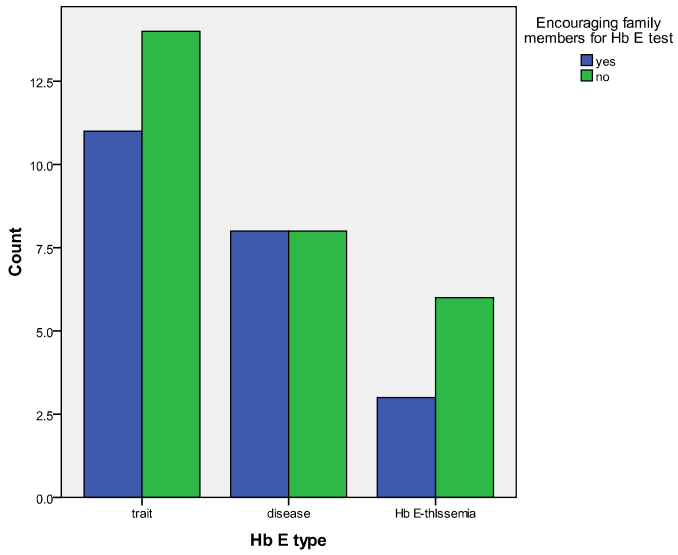

Fig. 7. Probands attempt to encourage family members for Hb E diagnosis-HB E wise

The Chi-Square test for independence was used to find the relationship between probands Hb E type and encouraging family members. The null hypothesis is "there is no association between probands Hb E type and encouraging family members". The results of cross tabulation (Table 7) revealed that, the majority of respondents don't encourage their family members 64% (32) even after they get tested positive for Hb E type. It is seen from the table that majority of the probands under Hb E trait group, 34% (17) have no intension of taking their family for diagnosis even after it is mentioned in the reports that it is mandatory to bring their family for diagnosis. (Doctors also have never focused on asking the proband to bring his family members for check-up) and only 16 % (8) of Hb E trait people have felt it necessary to get their family members diagnosed. In Hb E disease group total no of probands are 32% (16) of which 14% (7) of the respondents got their family diagnosed and 18% (9) of the respondents never took family members for diagnosis. InHb E/βThal group total no of respondents are 18% (9) out of which only 6% took their family members for diagnosis and rest 18%(9) never took family members for check-up(few Hb E/βThal are children whose parents though are aware of its consequences never took other family members for check-up and have no plans to do so). In overall, the average numbers of probands who felt it necessary to get their family members diagnosed irrespective of Hb E type they have, are 36% (18) and 64% (32) never took family members for diagnosis. In order to find whether there is any significance difference between Hb E type and encouraging family members, the Chi-Square was used to test the association between these two variables.

The Pearson Chi-Square value (Yeates Correction value)is 0.611 with an associated significance level of 0.737 ($p > 0.05$), this indicates clearly towards null hypothesis which is leading to the conclusion that there is no association between probands Hb E type and encouraging family members for diagnosis. The Cramer's V value is 0.111 also indicates the effect of Hb E type on encouraging family members is small.

Conclusion

Out of all the probands, it is seen that Hb E/ β thalassemia patients feel tired followed by probands with Hb E disease. Among the age groups, 'above thirty' feel tired in greater percentage followed by '15-30' age groups. All the probands which were suffering with these disorders they find it difficult to look after the needs of the family which is directly affecting their quality of life. Haemoglobin E/ β thalassemia and Hb E diseased people considerably felt deprived of social and personal life. Most of the subjects have been advised by the doctors to be on lifetime folic acid supplements irrespective of their Hb E type. Though major numbers (66 %) of subjects are on medication, a significant number (34 %) are not taking any kind of medication even after doctors' advice. Out of nine Hb E/ β thalassemic patients,seven are on medication while two patients have stopped taking medication due to poor economic conditions.

Though greater number of probands family member approached doctor for the diagnoses of Hb E. This can be attributed to lack of awareness about the haemoglobinopathy to the subject and family members. Most of the doctors whom the subjects approached have never as such advised the necessity of getting all the family members of the subject tested for Hb E. Doctors are failing in allowing people to know the impending danger the Hb E and its possible health impacts on life. Haemoglobin E has the capability to combine with other hemoglobinopathy which are mostly lethal. It is very much important to create awareness among the tribe to have a healthy progeny in future. Furthermore not having a testing centre in

the area is enhancing the problem, as most of them are economically backward and cannot incur the cost of the test else were.

REFERENCES

Balgir, R. S. 2014. "Is Hemoglobin E Gene Widely Spread in The State of Madhya Pradesh in Central India? Evidence from Five Typical Families", *Page Press Italy,* Vol.6 (1): pp 1-7.

Christopher Thomas S, Claire Dikson F Weiss Matchell J. 2013. "Hemoglobin Variants: Biochemical Properties and Clinical Correlates" *Cold Spring Harbour Perspectives in Medicine,* Vol. 3(3): pp 1-8.

Das M, 1993, *"Physical Anthropology of the Tribes of Northeast"* Kamala Raj Enterprises, Ed IV: pp 183.

Weatherall D J, Allen A, Fisher C, Premawardhena A, Peto T, Allen S, Arambepola M, Thayalsutha V, Olivieri N. 2010. "Adaptation to Anemia in Hemoglobin E-β Thalassemia", *Blood,* Vol. 116:pp. 5368-5370.

Weatherall D. J, Clegg J. B. 2001. "Inherited Haemoglobin Disorders: An Increasing Global Health Problem", *Bull World Health Organ*, Vol. 79: pp. 704-712.

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