Post Counselling Follow-up of Thalassemia in High Risk Communities

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In India the incidence of beta thalassemia trait in general population is about 3%. There are a number of communities in India such as Sindhi, Lohana, Khoja, Bhanushali, Punjabi, Jain, Muslim and Bengali in whom the incidence of beta thalassemia trait ranges between 8% to 15%. The high incidence can be attributed to consaguinity and endogamy practised in these communities. It is evident that if awareness about the disease is not created in these communities, the number of beta thalassemia major children born will be much higher than the present estimate of about 8,000 to 10,000 per year(l). Laboratory methods are available to test individuals for trait status and to conduct prenatal diagnosis of the fetus in the first and second trimester of pregnancy(2). The birth of thalassemia major child can be prevented by medical termination of pregnancy (MTP)(3). Preventive measures have already been adopted successfully world wide especially in Cyprus and Sardinia where the disease has been almost prevented(4).

In prevention of beta thalassemia, social scientist and counsellor have a major role to play. Under the awareness programme of Research Society of our Institution, since 1985 we have held 50 camps in the high risk communities. The present report evaluates the post counselling follow-up of thalassemia in these subjects.

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Subjects and Methods

Camps were held with two major objectives, namely, to bring awareness about the disease in the community, and to induce the individuals to get their blood screened. They were held for high risk communities in their respective residential areas, clubs, offices, colleges and women clubs during the period 1985 to 1990. Efforts were made to involve participation from individuals or heads of community and the well wishers. Whenever possible, a medical person from the community was involved as a link to induce the people to participate in the camps and get the blood test done. Inspite of these precautions, there was a considerable opposition from the elders of the community. In view of the hereditary nature of the disease, the families did not want to get themselves branded as thalassamics due to the fear of social stigma and the difficulties it would create in getting the girls married. With repeated attempts, it was possible to hold the camps and get the blood tested.

Non-trait reports were handed over to community leaders while the traits were asked to meet the counsellor along with the family, friends or close relatives for detailed discussion and inductive screening (screening of siblings and family members). The inheritance pattern of the disease was re-emphasized.

The follow up of a random sample of traits and non-traits was conducted *5-7* years after holding the initial awareness camps. The sample size consisted of 70 traits and 127 non traits from both sexes,

the age group being between 15 to 35 years. The follow up was rather difficult as during the intervening years the counseless had changed their addresses. Some had left the city due to employment opportunities. A minimum of four to ten attempts were made to contact the counselees. A self sufficient questionnaire was filled for each individual with special reference to the ability to recapitulate the information imparted in camps and the attitude towards the disease and it's prevention. The data was subsequently analyzed.

Results

Traits (70) followed up 5-7 years after counselling belonged to Lohana (n=13), Khoja (n=8), Jain (n=20), Bhaunshali (n=5), Sindhi (n=8) and low risk communities (n=16). Non traits (n=127) followed up after awareness camps belonged to Lohanas (n=17), Khoja (n=47), Jains (n=14), Bhanushali (n=28), Sindhi (n=ll) and low risk communities (n=4). Thirty six traits and 73 non traits (almost equal percentages) had low level of education; none of the responders was illiterate *(Table I)*. Similarly, totally 31 traits and 73 non-traits (almost equal percentages) belonged to lower socio-economic class. However, considering the per capita income of the family, none of them were below poverty line. The. educational and economic background of the respondee did not affect their understanding of the disease either way. The traits were centainly aware of economic implications of the disease.

Response of Non-Traits

Seventy per cent of the non-traits from high risk community who responded to the questionnaire could recall obtaining the information on the disease only from the awareness camps while 24% had heard about it also from doctors, neighbors and friends. Eighty seven per cent of individuals from this group knew about beta thalassemia major and minor status and the hereditary nature of the disease *(Fig. 1)*. Eighty five per cent non traits knew about the treatment of the disease while only 38% were aware of prenatal diagnosis. It was in-

TABLE I–*Personal Information of the Respondees*

Respondee Characteristics		Traits		Non Traits	
		No.	(%)	No.	(%)
Sex	Male	39	56	50	39
	Female	31	44	77	61
Age (yr)	15-25	49	70	60	47
	26 and above	21	30	67	53
Education					
	upto SSC	36	51	73	57
	above SSC	34	49	54	43
Income (Rs.)	≤ 3000/- p.m.	31	44	73	57
	> 3000/- p.m.	39	56	54	43
Marital status	Married	26	37	57	45
	Unmarried	44	63	70	55

SSC-Senior School Certificate.

teresting to note that 60% of non trait individuals knew that thalassemia trait is not a disease and it does not require treatment.

Response of Traits

Compared to the non-traits, the traits were very well aware of the disease *(Fig. 1).* Forty six per cent of them got all their siblings tested while 11% could not get a few siblings tested because of migration. It was a matter of concern that about 42% did not inform the siblings about their trait status and therefore, did not induce them to get themselves screened. All the traits were aware of beta thalassemia major and minor status of the disease, inspite of the fact that none of them had a major sibling or a relative. They were also aware of the possibility of prenatal diagnosis. The main stumbling block was the parents who insisted that the thalassemia minor status should not be disclosed to the in-laws. Out of 70 traits followed up from this group, 26 had married since the awareness camps. Sixteen males and 8 females did get their spouses tested, though mostly after marriage. The two who did not get their spouses tested fortunately had healthy children and did not wish to extend their family.

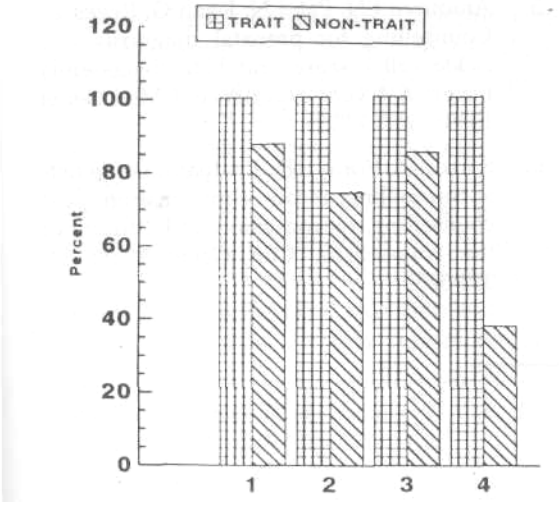

Fig. 1. Per cent respondees (traits and non-traits) giving correct information about: (1) Thalassemia as a disease; (2) Its hereditary nature; (3) Treatment of thalassemia; and (4) Prenatal diagnosis of thalassemia.

Out of 44 unmarried traits, 22 males and 18 females did not want to get their spouses tested before marriage. However, they promised that they will do so after marriage. A large number of traits (93%) favored that the parents should know about thalassemia minor status of their child. Fifty three per cent were of the opinion that the relatives, should also know while 47% felt that the relatives may spread the information amongst the community which might ostracise the trait family. Amongst the married trait, 88% shared the information with their spouses. Four girls were afraid of asking their spouses for blood testing before marriage. All the traits were of the opinion that genetic counselling should be offered before marriage. They promised to undergo prenatal diagnosis, if their spouses happened to be traits and agreed that medical termination of pregnancy (MTP) is the only alternative to control the disease.

Discussion

From this data it is evident that even after a gap of 5 to 7 years the healthy population in high risk community is aware of beta thalassemia as a disease and its treatment and prevention. However, they have not paid much attention to the availability of prenatal diagnosis of the disease as they were not directly concerned. On the other hand the traits seem to be well aware of all aspects of the disease including prenatal diagnosis and prevention. They seem to have used the information in their marriage and got their spouse tested.

Considering the Indian social and

cultural pattern, awareness programmes and genetic counselling in high risk communities are the only powerful and economic tool to control thalassemia. This method imparts the information to the target population without creating undue fear and concern, and takes into consideration the social structure and taboos, religion and economic aspects(5). Major constrains are poverty and illiteracy although these factors were not encountered in the present sample. An additional important factor to be considered is the influence of elderly members of the family. The youths including girls, appear to be more enlightened and awakened. Their participation in the awareness programme is very essential. It is important to note that with proper approach even less literate traits as well as non-traits can retain important information. Traits naturally are more conscious because of fear of transmitting the disease(6). Most of the married traits got their spouses tested and were prepared for prenatal diagnosis.

In conclusion, counselling high risk communities is a useful strategy for control of thalassemia.

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