AWARENESS OF PARENTS REGARDING BETA THALASSEMIA MAJOR DISEASE

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Date Submitted: January 22, 2015
Date Revised: May 29, 2015
Date Accepted: May 30, 2015

ABSTRACT

OBJECTIVE: To determine the level of awareness among the parents of children with Thalassemia major regarding prevention, treatment options and complications of disease.

METHODS: This multi-centric KAP study was conducted in Department of pediatrics Peshawar Medical College, Fatimid thalassemia Centre and Hamza thalassemia center Peshawar from June 2011 till December 2011. Total of 200 parents were selected as non-probability consecutive sampling. All the data was collected on structured proforma and analyzed on SPSS version 20.

RESULT: Out of the 200 patients who attended the transfusion centers, 76 (38%) were accompanied by mothers while 124(62%) were accompanied by their fathers. One hundred and twenty two parents were having no formal education, 56 were matriculate, 18 were Bachelor and 4 were having master degree. All the 200 parents (100%) knew that this disease need repeated blood transfusion and blood should be screened against hepatitis B and HIV. Although 68(34%) parents already knew that they have positive family history of thalassemia, 58 parents (85.2%) had not screened themselves while 10 parents (14.4%) screened themselves. Although 74% had knowledge about prenatal screening but only 11% considered it acceptable religiously and none of the couple opted for it. One hundred and eighty four (92%) parents were aware that iron over load is a complication of thalassemia while 16 (8%) had no knowledge regarding this complication.

CONCLUSION: Parents knowledge regarding beta-thalassemia was appropriate but there is a lot of space for further improvement in the existing attitudes and practices of parents of children with thalassemia.

KEY WORDS: Thalassemia Major, Parents' Awareness, Chelating Agent, Bone Marrow Transplant, And Blood Transfusion

THIS ARTICLE MAY BE CITED AS: Ali S, Saffiullah, Malik F. Awareness of parents regarding beta Thalassemia major disease. Khyber Med Univ J 2015; 7(2): 72-75.

INTRODUCTION

B-thalassemia major is one of the commonest, genetically transmitted hemolytic anemia.[1,2] Five out of 100 people in Pakistan are suffering from thalassemia. The disease burden in Pakistan is estimated to be ranging between 50,000 to 100,000 patients. Around 6000 babies are born annually with thalassemia in Pakistan.[2]

Consanguineous marriages are quite common in our society due to cultural reasons and the close netted family system. This is resulting in increasing the disease burden with every day passes. Due to our cultural setup, people remained reluctant to opt for the pre-marital thalassemia screening even being aware of the nature of its inheritance, having thalassemia in the first cousins and despite of the current legislations in Pakistan, requiring pre-marital thalassemia screening for every couple.[3]

Prenatal screening for thalassemia is available in Pakistan for over a decade now but unfortunately very few couples are aware of this screening. Again the higher cost of this screening further limit its use by general public.[4] Ironically it is also remained a fact that even after doing the prenatal screening for thalassemia, the religious, ethical and cultural taboos usually do not allow the couple to exercise the option of termination of pregnancy.[5,6]

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]

The definitive cure of thalassemia is bone marrow transplant, the facility that is available in very few centers of Pakistan. The average cost of bone marrow transplant ranges from U$ 25,000-40,000 and unfortunately it's beyond the resources of large proportion of our patients.

With the high disease burden of thalassemia, our low socioeconomic 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.[8]

Keeping in mind all the available treatment options, we are definitely left with no other option but prevention of this disease because it remained very true as for as thalassemia is concerned that "prevention is better than cure".

The rationale of our study is based upon the research question that what is the level of medical and social awareness for this debilitating disease among parents of thalassemia as so far no study has been conducted in present set up. The results of this study will help to determine the areas needing further improvement in public awareness campaigns as part of national thalassemia prevention programs. This study was planned to determine the level of awareness among the parents of thalassemia regarding the prevention, treatment options and complication of disease.

METHODS

It is a multi centric KAP study conducted in the department of pediatrics Peshawar Medical College, Fatimid thalassemia Centre and Hamza thalassemia center Peshawar from June till December 2011.

Two hundred parents of β-thalassemia major patients were included in this study by non-probability consecutive sampling technique. We included either of the accompanied parents of patients irrespective of the gender. We excluded patients with all other hemolytic / non-hemolytic anemia and non-consenting parents/ guardians accompanying the thalassemic children. Parents were interviewed according to preformed structured proforma to assess their knowledge regarding the disease, preventive measures and treatment modalities. They were also assessed for their attitude and practices towards the treatment and complication of treatment of thalassemia. All the collected data was analyzed on SPSS version 20.

RESULTS

Out of the 200 patients who attended the transfusion centers, 76 (38%) were accompanied by mothers, while 124(62%) were accompanied by their fathers. One hundred and twenty-two (61%) parents were having no formal education, 56 (28%) were matriculate, 18 (9%) were Bachelor and 4 (2%) were having master degree.

The answer distribution of parents regarding their knowledge about the hereditary nature of thalassemia is shown in Figure 1.

Out of 200 parents, 192 (96%) parents had 1-3 children suffering from thalassemia major while 8 (4%) parents had 4-6 children with thalassemia. All the 200 parents (100%) knew that this disease need repeated blood transfusion and blood should be screened against hepatitis B and HIV.

Majority of parents (n=132; 66%) had no knowledge of another person with thalassemia major in the family while 68 (34%) of parents were aware of positive family history of thalassemia major. However, out of these 68 (34%) parents who were aware of positive family history of thalassemia, 58 (85.2%) parents had not screened themselves before marriage and only 10 parents (14.4%) had pre-marital screening for thalassemia.

When the parents were enquired about the knowledge regarding the prenatal screening for detection of thalassemia gene, 148 (74%) parents were aware and 52 (26%) were not aware of prenatal screening in thalassemia. Although 74% had knowledge about prenatal screening but only 11% considered it acceptable religiously and none of the couple opted for it.

One hundred and eighty four (92%) parents had the knowledge that iron over load is a complication of thalassemia while 16 (8%) parents had no knowledge regarding this complication. However upon enquiring, regarding the attitude of using desferroxamine on regular basis, their answer is shown in table 1. Affordability was the main reason for not using desferroxamine.

Although 100 % of respondents knew that their child can get hepatitis B virus (HBV) due to repeated blood transfusion and the significance of blood screening

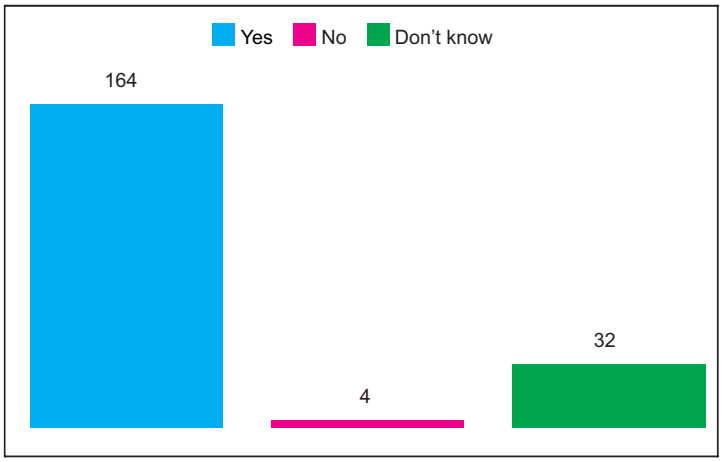

Figure 1: Knowledge about the hereditary nature of thalassemia n=200

TABLE I: ATTITUDE OF USE OF DESFERROXAMINE IN THALASSEMIA

How frequent Desferroxamine was used	No of patients (n=200)	Percentage
Never	38	19%
Daily	48	24%
Weekly	64	32%
Monthly	28	14%
Infrequent	22	11%
Total	200	100%

but only 124 (62%) patrents showed psitive attitude and practice towards vaccination for HBV while 76 (38%) were of not in favour of HBV vaccination of their children.

One hundred and twenty (60%) parents had the knowledge about bone marrow transplant as a treatment option while 80 (40%) parents had no knowledge about bone marrow transplantation. Thirty two (16)% parents had no idea about different blood donation centers in their town even having one or two thalassemia children.

DISCUSSION

Thalassemia is an inherited disorder that results from abnormalities in the synthesis of the hemoglobin molecule contained in red blood cells. It can be a potentially preventable disorder in our community especially after effective legislation done by the parliament of Pakistan. Our study showed good knowledge of parents regarding thalassemia though their attitudes and practices regarding the disease need much more modifications.[9] Keeping in mind the disease burden and limited treatment options, prevention of thalassemia is the only effective option we have left with in our community. Creating awareness among parents regarding thalassemia will help them modifying their attitude and practices. This will help in prevention and decreasing the disease burden in our community.

The Strength of our study is that it is a larger sample sized, multicentric KAP study from our province. Due to the poor literacy rate and varied IQ of the parents, it is mostly a subjective KAP survey with probable inter-observer bias.

The word thalassaemia (thalassa-anemia) deriving from the Greek word "thalassa" meaning sea i.e. the anemia occurring in countries around the sea. In Pakistan, we have approximately 9.8 million people suffering from thalassemia minor and they have the ability to transfer thalassemia major to their upcoming generation if their spouse also carries thalassemia minor gene.[10]

Poor literacy rate is the biggest problem of Pakistan since its creation in 1947. Although the literacy rate of regional countries like Sri Lanka, Iran and Nepal is very good and according to the census 2014,the literacy rate in Pakistan is 56% but those who can read and write his name is considered literate in Pakistan, so this parameter is not comparable with developed nation. In our study, we have found that 122 (61%) of parents were having no formal education which is comparable with national literature as Arif F et al [11] has reported it 66.7%, while it was reported around 49 % by Bandyopadhyay B, et al in their study.[12]

In our study, we have found that 82% of parents knew about the hereditary nature of disease that is much better than studies done by Ishaq F et al [13] and Arif F et al [11] with the percentage of 44.6 and 15 respectively.

Sixty eight (34 %) of our parents already knew that they have positive family of thalassemia but only 10 parents screened themselves for thalassemia before marriage that is comparable with study done by Miri-Moghaddam in Iran where 78.6% couple did not screen themselves despite positive family history.[14] It is contrary to more developed countries like Turkey, where with effective legislation, the percentage for it increased from 30 to 86 in 10 years.[15]

CONCLUSION

Parental awareness regarding various aspects of beta thalassaemia is of great importance not only for the proper management and improved quality of life of the patient with thalassemia but also for the prevention of further children with thalassemia major in the family. But there is a lot of space for further improvement in the existing attitudes and practices of parents of children with thalassemia.

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AUTHOR'S CONTRIBUTION

Following authors have made substantial contributions to the manuscript as under:

SA: Concept & study design, acquisition of data, drafting the manuscript, final approval of the version to be published

AB: Acquisition of data, drafting the manuscript, final approval of the version to be published

FM: Analysis of data, critical revision, final approval of the version to be published

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

CONFLICT OF INTEREST

Authors declare no conflict of interest

GRANT SUPPORT AND FINANCIAL DISCLOSURE

NIL

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