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Mini Review

## Thalassemia Major: A study on the perception of parents about disease

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## INTRODUCTION

The article, "Assessing Parental Knowledge about Thalassemia, in a Thalassemia Center of Karachi, Pakistan", was published in "The Journal of Genetic Counseling"; in December 2015 issue [1]. The study explored the level of knowledge about the disease among the parents of the suffering children. This could be directly proportionate with the poor literacy rate among the study population. The article also stated Thalassemia as second leading haemoglobinopathy (disease and disorders of haemoglobin) after Sickle Cell Anemia by indicating its occurrence of 1.5% of the global population; whereas 1 in 4 per 1000 infants suffer from this disease [2]. This genetic-hereditary disorder is found to be one of the most common inherited disorder in Pakistan while observing the previous researches which explicit a more than 4000 births per year; they also reported an approximate of 5.3% of Beta-Thalassemia carrier rate, with a variation from 1.8% to 8.0% on regional basis [3-6]. The core area of reasons behind this misery was reported as consanguineous marriage. Inadequate knowledge of parental diagnosis (especially when the partners are thalassemia minors), religious stigma related to the genetic testing as well as termination of pregnancy, Societal and Cultural values that prohibit one from being tested as thalassemia carrier, low literacy rate that forbids to adopt new concepts and trends in order to take care of one's health; the most significant reason was found as a lack of a structured awareness and prevention program for thalassemia and its advocacy. Collectively, these above could be the factors or reasons that may cause the high prevalence rate of the disease [7-13].

## RESULTS AND DISCUSSION

The result about the parental knowledge or perception about the thalassemia could be exhibited into two arms: one is about the disease and another one is about the disease treatment. The study pointed out that out of the 172 parents of existing patients 40% showed lower scores in the pre - tested and validated Thalassemia knowledge questionnaire [14]. Here, language barrier might be a chance of lower scores because the questionnaire was in Urdu Language; hence, it could be a significant variable that might affect the results, since Urdu was not the native language of all of the participants (that is parents). That might cause an understanding problem leading to compromised, incorrect and silent answers that further tend to generate low grades of knowledge. This hypothesis was supported by the ethnic distribution of results such as the higher score of Urdu Speaking parents ( $21.6 \pm 4.41$ ) as compared to the Siraiki's ( $17.9 \pm 4.48$ ) and Pathan's ( $17.2 \pm 4.34$ ). Hence, in our opinion the results of this research could be different had it been conducted using the native language. While evaluation about the disease treatment was tried to be explored, it was found that 86% of the parents are well aware about options of the disease treatment mainly blood transfusion. Such a high score must be correlated with the fact that those are the parents whose children are receiving treatment at an institutional set up. The continuous exposure and visit to a systematically and objectively planned facility is the biggest factor of such high score of awareness about the disease treatment. The doctors, at the center, as per the policy, are having first detail discussion at the time of diagnosis, and then regular sessions in groups and regular session by Psychologist are carried out. Therefore, this structured program has produced expected results. This is, hereby, strongly stated, that a well-structured awareness and prevention program for thalassemia must be designed for the general public as well. The article pointed out that at the participated center, in order to be familiar with the treatment modalities patients and

their accompanying parents received regular genetic counselling and need-based psychiatrist counselling sessions, which could be a major reason for the results stated. One of the observation in the results also pointed out that 60% of the total participants thought that Thalassemia was a sexually transmitted disease and 50% believed it was an allergic reaction, yet the parents of the children suffering from it hardly were aware of the causes nor the prevalence of this disease [3,4]. This is directly related to the educational level and hence the socioeconomic status of the family as proven by the research article; another important point to be noted was the lack of knowledge of and awareness of the causes of Thalassemia. As far as Thalassemia minor is concerned 74% of parents answered about as a disease that became a cause of an increased risk of infection and illness, whereas 50% believed that because of Thalassemia minor a patient could not lead a normal life. This is again a kind of an audit to understand the overall knowledge and also points out where to work to avoid spreading of wrong knowledge among the public and thalassemia families. The article correctly noted that mostly the parents were more focused on the disease although they could see affecting their child but were not focused on the type and the implementation of strong prevention program; secondly the health education provided at the participated center was also more focused on Thalassemia major, for which blood transfusion and hence medical intervention is mostly required. Mutation in the Fr 8-9(+G) in the Pathan and Siraiki ethnic groups as pointed out in the article correctly states the two main causes as consanguineous marriages which are very much prevalent in these ethnicities and lack of education about this dilapidating disease.

## RECOMMENDATIONS

We strongly suggest that Pakistan is a high risk population for thalassemia with having neighbour countries like Iran, India, Afghanistan, and China with high prevalence of Haemoglobinopathies including structural variants. We propose as one of the solution could be the establishment of Thalassemia Workers Program at community level similar to the Lady Health Workers program (in Pakistan) that can help spread the information door to door especially in those areas where this disease is most prevalent, i.e. in the targeted ethnic group. The research thus conducted at the center although limited in its patients as compared to the whole of the Pakistani population, still sheds a light on Thalassemia as well as the knowledge about the disease and can be a major stepping stone for further such researches and such surveys should be conducted in other thalassemia centres all over Pakistan.

## CONCLUSION

In conclusion the articles summed up well that all the above stated causes, treatment modalities and education can be tackled by having culturally and linguistically appropriate health literacy material both in printed and verbal form that could provide the necessary education focusing on not just the parents of the children suffering from the disease but the general population as well.

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