KNOWLEDGE, ATTITUDE AND PRACTICES WITH RELEVANCE TO THALASSEMIA

Zafar Zaheer[1], Qamruz Zaman[2], Basharat Hameed[1], Saima Wazir[1], Muhammad Iqbal[2]

[1]Department of Economics, Institute of Management Sciences, Peshawar - Pakistan

[2]Department of Statistics University of Peshawar, Peshawar - Pakistan

ABSTRACT

Objective: Assessing Knowledge, Attitude and Practices of people of Khyber Pakhtunkhwa in relation to Thalassemia.

Material and Methods: Cross-sectional survey is conducted in Fatmeed foundation and Hamza Foundation of Peshawar from May 2012 to September 2012 with the help of structured questionnaire and interviews. Self-designed questionnaire is used to determine the demographics of the patients and gauge their knowledge and practices related to Thalassemia. However, questionnaire developed by Ratip and Modell (1996) is used to gauge the attitude of the parents of Thalassemic patients. The survey is conducted in the health centers in Peshawar that specialize in providing medical facilities to patients suffering from blood disorders. Logistic Regression and Chi Square test of Association is used to arrive at results

Results: attitude and practice towards treatment and other important actions such as family extension are greatly affected by the knowledge about thalassemia as well as by culture. Awareness about the pre and post marriage treatment supported by culture and religious beliefs for the potentially at risk families as well as general public is very necessary to facilitate the prevention of the disease.

Conclusion: The lack of awareness about the nature of Thalassemia in general public in combination with the cultural and religious influence affects the attitude and practices of people of Khyber Pakhtunkhwa negatively in relation to Thalassemia prevention.

Key Words: Thalassemia, KAP, awareness, logistic, regression.

INTRODUCTION

The rate of Thalassemia varies in different regions, broadly, it ranges from 2.2%-16% of the total population in different countries around the world[1]. In Pakistan the prevalence of Thalassemia in some areas is up to 8%. Despite a high prevalence, the knowledge about the disease is scarce. General literacy rate is low and knowledge about Thalassemia rarer. This leads to ignorance about the factors that may lead to spreading the disease even further. The knowledge about the disease may lead to a different attitude towards family extension. A study recently conducted in Iran about knowledge, attitude and preventive practices indicated that knowledge and attitude are positively correlated regarding the importance of calcium and vitamin D[2]. Such evidences indicate that the knowledge can play an important role to set the attitude and practices of thalassemics' parents. The prevention of the disease may be more feasible if masses can be educated about the chronic disease. A research study conducted in Kerman city reported that most of the population has poor knowledge about thalassemia and therefore more education is required to improve quality of care in thalassemics[3].

However knowledge may play an important role on one hand, the cultural beliefs and misinterpretation of religious commands by the general population has resulted in increasing rate of Thalassemia prevalence in the country. For instance, consanguineous marriages are culturally encouraged[4]. However, such marriages have been scientifically proven to result in genetic deformity in children of such couples[5]. Qamruz Zaman et al. reported in a research article that inter-family marriages play an important role in thalassemia confirming many research studies about consanguinity[6]. On the other hand it is a common belief that whatever calamity one is inflicted with is from divine[7]. Hence, abortion cannot be considered as an option if any deformity is reported in the fetus. Such beliefs cannot be opposed or questioned openly without creating social unrest. A research

Address for Correspondence:
Dr. Muhammad Iqbal
Associate Professor
Dept. of Statistics,
University of Peshawar
Cell: 0333-9589230
E-mail: miqbal_70@upesh.edu.pk

study conducted in Khyber Pakhtunkhwa reported that awareness about family planning and the test during pregnancy test plays an important role in controlling the chronic disease[8].

In South Asia, cultural norms are prevalent and sons are still preferred over daughters, similarly, the larger the family, the stronger it is deemed. However, identification of Thalassemia genes in a family may affect this perception. Parents of affected children may not want to extend family for probability of having other Thalassemic children. Thus knowledge of transferring the hereditary disease to their children may or may not affect the attitude of the parents towards family extension. In any case i.e. if the attitude is affected or not, the behavioral patterns need to be studied for future reference. Similarly other cultural and religious beliefs may contribute to the factors that may affect Thalassemia prevention.

It has been reported that the carrier rate is 7% in Khyber Pakhtunkhwa. Therefore it is important to study the knowledge of the people of Khyber Pakhtunkhwa related to Thalassemia, their attitude towards the disease and the aspects related to it; and their practices that may contribute to increase the prevalence of the disease or impede it. For this purpose, cultural and religious beliefs are taken as control variables to get a holistic and realistic picture of how people behave in the region and why?

MATERIAL AND METHODS

The population for the study was the families with Thalassemics in Khyber Pakhtunkhwa. A self-designed questionnaire was used to measure the knowledge and practices of the respondents. The questionnaire was developed to measure the knowledge attitude and practices of the affected families. Questions about abortion, social and family pressure, religious beliefs, cousin marriages and prenatal test were included. Attitude was measured with the help of the questions adopted from the questionnaire developed by Ratip and Modell. The questionnaire was administered with the help of trained enumerators; keeping in view the low literacy rate of the region.The survey was conducted at health centers in Peshawar using convenient sampling technique. Fatimid and Hamza foundation situated in Peshawar were visited in Peshawar. The information was thus collected from the recipients belonging to different districts of Khyber Pakhtunkhwa. KAP is divided into sub categories. These include knowledge about the nature of Thalassemia, its hereditary nature, higher prevalence of the disease in consanguineous marriages; attitude towards family extension, prenatal test, abortion and consanguineous marriages and towards tests for carrier identifications; family extension practice. Knowledge, attitude and practice are binary categorical in nature. Number of the affected child in siblings, time since the respondents (thalassemics' parents) are married, and prior relation with spouse (cousin or not) are included as control variables.

A total of 360 respondents were interviewed at Fatimid and Hamza foundation from May 2012 to September 2012 in Peshawar. Data went through cleaning process before the final analysis. Logistic regression was used for the analysis, supported by odds ratio and other descriptive statistics. The variables knowledge, attitude and practices (family extension) were kept binary categorical in nature to suit the requirement of statistical analysis.

RESULTS

The results show that the knowledge about the nature of thalassemia increases the odds of the effect on decision about the family extension by 2.47 against the lack of knowledge of the disease in presence of some control variables. The variable "number (order) of children" in the family was included in the model as a control variable. The odds ratio 0.516 shows that if the child is younger/youngest among the siblings, parents are more likely to say that their decision to extend family was affected. Most of the control variables are significant. However the main focus is on the variable Knowledge and its relation with attitude towards family extension.

The odds that a person with knowledge has extended the family are 2.758 times higher than no extension. The question arises that despite the fact that the affected family had the knowledge about the inheritance of the disease why was the family extended. For this reason other variable needs to be considered. Such as, the number of the affected child among the siblings shows that after the child was diagnosed for the disease, the family was still extended. It is observed that if the affected child is the eldest among the siblings the family is extended and the odds are two times higher than if the affected child is younger.

Prenatal diagnosis is not a common practice in Pakistan. It was evident in the target population where only 4% mothers went for prenatal test. In case the disease is diagnosed during pregnancy, 50% of the parents suggested abortion; 22% parents suggested treatment; 12.5% think that they should not plan more kids. Some parents showed religious inclination and stated their belief that the disease of their child is a test from GOD and one needs to be patient about it. 5% parents declared indecision and said that they have no idea about what should be done in such a situation. A

very small number however believe that it is not possible to diagnose the disease during pregnancy. When asked what advice they would give to a young couple who planned to marry but their blood test showed that they probably could have a child with thalassemia, 75% of the respondents advised not to get married. A few respondents said that such tests are not allowed in their area. Only 5% respondents advised precautionary measures. 2% believed that such calamities are from divine and are written in fate hence one cannot avoid them anyway so they should go for marriage. 73% respondent said that they will not allow their family members to marry a person who has thalassemic background. 18% said that they will allow consanguineous marriages in their family, even after being told that it might be risky, the remaining were neutral about the idea.

Four percent parents went for a prenatal test, and most of them were those who faced the problem in the beginning of their family extension. 98% parents said that the mother should go for a prenatal test. 94% parents are in favor of abortion if the prenatal test suggests that the child will be affected. Though these statistics are not very conclusive however it suggests that an early diagnosis and awareness about the nature of the disease may force the parents to go for a prenatal test and extend the family without taking a risk.

DISCUSSION

The results suggest that the decision to extend family is more affected for the parents who understand the nature of thalassemia. It is possible that the parents may be more conscious and afraid of the fact that their next child may also be affected. It has also been observed that those who claim their decision not to be affected was not because of the Thalassemic child but it may be because they were not planning on extending their family anyway. In our study 94% parents were in favor of abortion if the prenatal test suggests that the child will be affected however in another study conducted in London for abortion 100 percent couples agree[9]. If the disease is diagnosed in an early child, then the family extension is not affected by the diagnosis. The results coincide with our assumption that if the disease is diagnosed in an early child then the family will be extended even after identification of the risk that the rest of the children may have the same disease. However, if the birth of the child occurs later in the family then the family extension is stopped.these findings were consistent with other studies[10]. It is also supported by literature that South Asian families are usually large in number and parents hope to have a larger number of sons to achieve superiority over their relatives. Knowledge about the disease could not help proper practice, i.e. family extension.

It was noticed that knowledge about the nature of Thalassemia has a positive effect on attitude. Those parents who understand the nature of thalassemia are willing to test their other children for carrier identification as compared to those who still do not know the nature of the fatal disease that their child suffer from. Some supplementary analysis was conducted to obtain the opinions about abortion, pre natal test and cousin marriages. Results have been discussed in previous section. These findings are a ray of hope for the future of Thalassemia prevention. In this study the number of the parents who recommended termination of pregnancy is quite high, in case diagnosis declares the baby to be Thalassemic. This can be attributed to the psychological pressure that the parents face. They would advice not bringing a life into this world that is constantly dependent on blood transfusion. If the experience of these parents is shared with proper counseling and awareness then the couples at risk can be saved from a lifelong misery.

Thalassemia is more prevalent in families where the spouses are cousins. However 56% of the respondents believed that it is not true, which indicates the lack of knowledge about the inheritance pattern of the disease. For further understanding a test of association was run between the knowledge and the respondent's prior relationship with his/her spouse. An Odds ratio of 3 suggests that those couples who are cousins have a 3 time higher knowledge than those who are not cousins by relation. 69% said that they will not oppose cousin marriages in the family. 67% respondents believed that cousin marriages should be practiced. in the rest of the world the consanguity marriages are less in number so the chances of this disease in siblings are very less.[11,12]

CONCLUSION

Awareness and knowledge among affected families plays an important role to change the attitude of people towards family extension and reduce the chances of Thallesemia to run in family. the prevention and control of the chronic disease can be achieved by an ongoing holistic approach.

Future recommendation

A similar research may be conducted in general population, particularly in schools colleges and universities to assess the knowledge about the disease.

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AUTHOR'S CONTRIBUTION

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

Zaheer F: Concept and Principal Investigator.

Zaman Q: Supervision.

Hameed B: Develop questionnaire.

Wazir S: Literature review.

Iqbal M: Data Analysis, methodology,proof reading and manuscrpt writting.

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.

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