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**Original Article**

# Impact Of Population Screening Programs On The Knowledge, Attitudes And Practices Regarding Prevention Of Thalassemia

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## ABSTRACT

Beta Thalassemia is the most common genetic disorder in Pakistan. **Objectives:** To assess the knowledge, attitudes and practices of parents of children suffering from Thalassemia with regards to disease prevention. It also determined the degree of social and religious opposition faced by these parents during implementation of preventive practices **Methods:** A descriptive cross-sectional survey was conducted in the 36 districts of Punjab via nine regional centers of Punjab Thalassemia Prevention Project. 248 parents of Beta Thalassemia Major and Intermedia were interviewed using a pre-designed pre-tested structured questionnaire. All statistical analyses were conducted using Statistical Package for Social Sciences (IBM SPSS 23.0) **Results:** 83.5% of the respondents had adequate knowledge and 98.4% had positive attitudes. Knowledge and attitude were positively correlated (p=0.00). 93% opted for prenatal diagnosis and 91% opted for termination of affected fetus. Among these individuals 12% faced opposition from their family members when they went for diagnostic testing and this opposition rose to 20% when they had to opt for termination. The local religious clerics opposed prenatal diagnosis in 3% of the cases and termination in 7% of the cases **Conclusions:** When compared to previous studies the knowledge, attitudes and practices of our study population was better. Thus, population screening programs have a positive impact on knowledge, attitudes and practices of caregivers of Thalassemia patients. However, social and religious opposition needs to be countered for further implementation of effective preventive practices.

## INTRODUCTION

Beta Thalassemia is a hereditary, chronic hemolytic anemia resulting from partial or complete deficiency in the synthesis of β-globin chains (that compose the major adult hemoglobin) leading to anemia and extramedullary hematopoiesis [1]. This results in lifelong blood transfusion dependency and consequent need for iron chelation in affected individuals.

Pakistan shares a significant burden of this globally prevalent disorder, Thalassemia being the commonest hereditary hemoglobinopathy in the country [2]. Although there is a lack of a proper registry, it is estimated that around 100,000transfusion dependent Thalassemia major patients exist in the country, with an annual increase of 5000-9000 patients [3]. The estimated carrier rate is 5-8%, with around 10 million carriers in the total population [4]. On an average, optimum treatment costs around US$4500 per year per child [5] and one fourth of the donated blood in Pakistan is consumed by Thalassemia patients [6]. The average life expectancy of these patients is around 10 years [7]. Thus this disease has a significant burden on the limited health and transfusion services of our resource limited country.

To curb the disease burden, prevention by pre-marital screening for carrier identification and prenatal diagnosis followed by termination of affected fetus in early pregnancy can be done. The carrier percentage of Thalassemia gene is 5-6 times higher in index families because intermarriages lead to gene entrapment and proliferation [8]. Therefore, targeted prevention and awareness sessions in these index families can reduce the morbidity, mortality and the prevalence of Thalassemia in a more cost effective manner.

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Various studies have concluded that the level of awareness regarding the disease even among affected families is inadequate in Pakistan [9]. Parents have poor knowledge regarding the genetic nature and mode of transmission of the Thalassemia [10] and also lack positive attitude and practices with regards to its prevention i.e. prenatal diagnosis and termination of affected fetus [11].The reasons behind this include low literacy rate, lack of awareness programs, poor access to health facilities, economic constraints and religious and socio-cultural elements [12].

In Pakistan, Punjab Thalassemia Prevention Program (PTPP) is the only government sponsored program offering genetic counseling, premarital and pre-natal screening services for Thalassemia major families as well as the general population at provincial level [13]. All services are provided free of cost in all 36 districts of Punjab, the most populous province of Pakistan via its 9 regional centers [14, 15].Since 2012, PTPP has screened more than 9774 families and conducted more than 5896 pre-natal diagnosis tests (Chorionic villus sampling) till Feb'2021 [16]. All carrier patients receive genetic counseling sessions and awareness seminars are also conducted to educate the masses. By taking a representative sample from a varied socio-economic and culturally diverse population this study aims to determine the knowledge, attitudes and practices of parents of children affected from Thalassemia regarding disease and its prevention. It also assesses how socio-cultural and religious elements influence them when opting for preventive practices like prenatal diagnosis (PND) and termination of pregnancy(TOP).

## METHODS:

A descriptive cross sectional study was designed and conducted by the regional centers of PTPP from September 2020 to February 2021. All children diagnosed by PTPP till date as Beta Thalassemia Major or Intermedia were shortlisted. These tests are conducted as part of PTPP's routine carrier screening facilities. The parents of these children, who gave informed consent to be part of the survey, were included. Parents of children suffering from other hemoglobinopathies apart from Beta Thalassemia were excluded. The research was approved by the Institutional Review Board and conducted in line with the principles of Declaration of Helsinki. A population size of 600 cases meeting the inclusion criteria had been identified during the specified period. Using published tables, with precision level of ±5%, confidence level of 95% and probability of 0.5, the estimated sample size was 240. The total numbers of interviews that had complete responses and were included in the analysis were 248. Non-probability convenience sampling was undertaken to enroll the study subjects.

### Data Collection Procedure

The study tool was a pre-designed, pre-tested structured questionnaire designed by a clinical hematologist, a psychologist and a public health professional and validated by a qualified biostatistician. The questionnaire included 40 questions divided into four major sections. These included demographics, knowledge (about disease, its genetics and its treatment), attitudes (towards disease and its prevention), and practices (related to disease prevention and the socio-religious hindrances faced in implementing them). All questions were close ended multiple choice type. The questionnaire was translated in Urdu (the national language of Pakistan) and validated for ease of communication for the interviewer and interviewee by following the process of forward and backward translation.

Parents fulfilling the selection criteria were interviewed face to face either at their homes, Thalassemia treatment centers or the PTPP regional centers as per their convenience. The interviews were conducted by PTPP field staff that were trained extensively beforehand to minimize interviewer bias and used detailed, structured interviewing technique.

The schedule was piloted among 20 individuals to assess its clarity, reliability & validity after which a few modifications were made and re-evaluation done. The content and construct validity of the questionnaire was confirmed by the research team and the reliability was confirmed by Cronbach's alpha test. A reliability coefficient of 0.82 was reported. The participants who were included in the pilot study were not included in the whole study sample.

### Data Analysis Plan

The responses of interviews were tabulated and frequencies calculated to understand the correct response rates per question. A knowledge scoring system was devised in which those respondents who correctly answered ≥ 9/15 knowledge questions (i.e. ≥ 60% score) were labelled to have adequate knowledge. Similarly an attitude score was devised, whereby those who answered ≥ 4/8 (i.e. ≥ 50%) of the attitude questions correctly were said to have a positive attitude. Correlation of some variables was studied using Pearson's correlation. ANOVA with Welch correction was used to study differences amongst different demographic groups with respect to knowledge and attitude. Games-Howell was used as post hoc to differentiate different groups after ANOVA. To test the hypothesis that an adequate knowledge of disease leads to a positive attitude, Spearman Correlation was used. To determine the degree of good practices and the opposition faced from their social, family and religious circle in their implementation, frequencies and percentages were used. A p value of $<0.05$ was interpreted as significant. All statistical analyses were conducted using Statistical Package for Social Sciences (IBM SPSS 23.0). The

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computerized data was encrypted to maintain anonymity.

## RESULTS:

A total of 248 interviews (of 131 fathers and 117 mothers), conducted in the nine divisions of Punjab were included in the analysis. The median age group was of 30-39 years. Punjabi (72%), followed by Saraiki (23%) was the most common ethnic group. 190 parents (77%) had a consanguineous marriage. Regarding the level of education 23% had no schooling and 21% had got primary education only. 79% of the respondents had a meager monthly income of less than PKR 25,000 (USD 150). Of the parents interviewed 59% had a single affected child, 25% had 2Thalassemia children and the remaining had more than 2 affected children in their family.

The knowledge section of questionnaire assessed the parents' knowledge about the nature of disease, its genetics and its treatment (Table 1). The majority of the respondents were well aware regarding the hereditary nature of Thalassemia (84%), a disease in which both parents need to be carriers (81%) and the risk of affected children being born is more in consanguineous marriages (81%). Majority of the respondents were also aware that the disease can be detected during pregnancy (86%), that a Fatwa (ruling by recognized authorities in the light of Islam) is available for termination of affected fetus before 16 weeks of pregnancy (71%) and that prenatal diagnosis can help in prevention of disease (94%). In summary, of the parents interviewed 83.5% had adequate knowledge regarding Thalassemia (≥ 60% score achieved)(Table 2).

| KNOWLEDGE QUESTIONS | Correct Response | |
|---|---|---|
| **Knowledge About Disease** | | |
| Is Thalassemia a disease of blood? | YES | 225 (91%) |
| Are there different types of Thalassemia? | YES | 162 (65%) |
| Do parents of children with Thalassemia show disease related symptoms? | NO | 61 (25%) |
| Is it possible to detect Thalassemia in fetus during early pregnancy? | YES | 214 (86%) |
| Is there a fatwa available for termination of Thalassemia Major Fetus before 16 weeks of pregnancy? | YES | 177 (71%) |
| Is Thalassemia preventable? | YES | 198 (80%) |
| Do premarital carrier screening and prenatal diagnostic testing help in prevention of Thalassemia? | YES | 232 (94%) |
| **Knowledge About Geneticsls** | | |
| Thalassemia a genetic disorder transferred from parents to children? | YES | 207 (84%) |
| Is it necessary that both parents be carrier for a child with Thalassemia Major to be born? | YES | 201 (81%) |
| What is the percentage of having a Thalassemia Major child in each pregnancy if both parents are Thalassemia Carriers? | 25% | 98 (40%) |
| Is there more chance of having Thalassemia children in cousin marriages? | YES | 201 (81%) |
| **Knowledge About Treatment** | | |
| Is Thalassemia Major Child dependent on lifelong blood transfusions? | YES | 235 (95%) |
| Can frequent blood transfusions lead to iron overload? | YES | 208 (84%) |
| Do Thalassemia Major Patients require regular medicine for iron overload? | YES | 219 (88%) |
| Is Bone Marrow transplant the only permanent cure for Thalassemia? | YES | 123 (50%) |

**Table 1:** Distribution of Study population according to knowledge about Thalassemia(n=248)

| Knowledge (15 items) | Number | Percentage |
|---|---|---|
| Adequate (Score ≥ 9 or 60%) | 207 | 83.5 |
| Inadequate (Score < 9 or 60%) | 41 | 16.5 |
| Attitude (08 items) | Number | Percentage |
| Positive (Score ≥ 4 or 50%) | 244 | 98.4 |
| Negative (Score < 4 or 50%) | 4 | 1.6 |
| Total | 248 | 100.0 |

**Table 2:** Knowledge and Attitude Scores of Thalassemia among study population(n=248).

When the attitudes regarding disease prevention were assessed (Table 3), 73% of the respondents agreed to avoid cousin marriages and 84% agreed on advising against marriages between two carriers in their family. 95% were willing for prenatal testing if a future pregnancy occurs, and 93% said they will terminate the pregnancy if the fetus is affected. 94% of the respondents agreed that both genders need to be tested as part of carrier screening. Thus, 98.4% of the respondents had a positive attitude towards disease prevention (≥ 50% score achieved) (Table 2). Age, gender, consanguinity, income and Thalassemia burden in household didn't have a statistically significant impact on attaining adequate knowledge or developing a positive attitude. With regards to education, no schooling was found to be significantly associated with inadequate knowledge and negative attitude (p= 0.00). Knowledge and attitude were moderately positively correlated (r=0.305, p=0.000). Thus, adequate knowledge of Thalassemia correlated with development of a positive attitude towards disease and its prevention.

| Attitude Questions | Correct Response | N (%) |
|---|---|---|
| Will you prefer Cousin/ inter-family marriages for your children and extended family members? | NO | 180 (73%) |
| Will you knowingly advise marriage of a Thalassemia carrier with another Thalassemia carrier in your family? | NO | 207 (84%) |
| If you are expecting a child, would you like to know the Thalassemia status of your fetus? | YES | 236 (95%) |
| If Pre-Natal Diagnosis reveals that your upcoming fetus is Thalassemia Major, will you opt for abortion? | YES | 236 (95%) |
| Should a Thalassemia couple (where both partners are Carriers) have children? | YES | 110 (44%) |
| Which members of the family will you prefer for Thalassemia carrier screening? | BOTH | 233 (94%) |
| Do you think it is important to do the blood test for Thalassemia (Carrier Screening) before marriage? | YES | 246 (99%) |
| Do you think it is important to create mass awareness among public about Thalassemia? | YES | 244 (98%) |

**Table 3:** Distribution of Study population according to attitude about Thalassemia (n =248)

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With regards to practices of Thalassemia (Table 4), 93% of the parents encouraged their family members to undergo carrier screening. Of the respondents, 138 had the opportunity to avail pre-natal diagnostic services in an upcoming pregnancy. Of these, 128 (93%) underwent PND and thus had good practice (Figure 1). Reasons of not undergoing testing by the remaining 10 parents included family, social or religious opposition, indecisiveness or delayed presentation at centers beyond 16 weeks of pregnancy. 50 out of 55 parents with a Thalassemia Major fetus opted for TOP (91% good practice). In conclusion a significant majority (81-93%) of the participants (who found the opportunity) had good practices. Of the 138 respondents who had an opportunity to undergo PND, 12% faced family and social opposition and 3% faced religious opposition from religious clerics. With regards to termination of pregnancy 20% faced opposition from their family and social circle and 7% faced opposition from clerics (Figure 1).

| Information sought | Yes | No | Did not find opportunity |
|---|---|---|---|
| Did you encourage your other blood relatives to get themselves and their children tested for Thalassemia? | 230 | 17 | 1 |
| Did you discourage the marriage of two known Thalassemia carriers in your family? | 59 | 14 | 175 |
| After knowing Thalassemia as genetic disorder in your family, did you opt for pre-natal testing? | 128 | 10 | 110 |
| Have you opted for termination of pregnancy of a known Thalassemia Major fetus? | 50 | 5 | 193 |
| Did you face opposition from other members of your family and/or social circle with regards to PND? | 17 | 121 | 110 |
| Did you face opposition from other members of your family and/or social circle with regards to TOP? | 11 | 44 | 193 |
| Did you face opposition from religious cleric with regards to PND? | 4 | 134 | 110 |
| Did you face opposition from religious cleric with regards to TOP? | 4 | 51 | 193 |

**Table 4:** Distribution of Study population according to practices about Thalassemia(n=248)

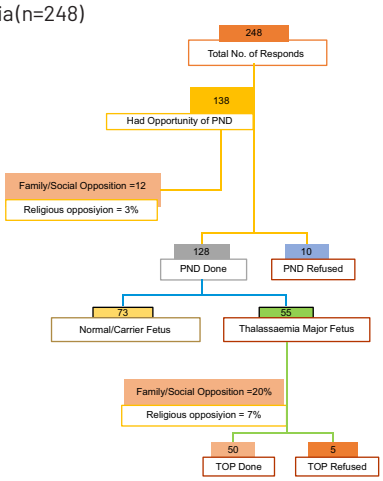


**Figure 1:** Prenatal Diagnostic Testing (PND) and Termination of Pregnancy (TOP) Practiced by Parents of Beta Thalassemia Major/Intermedia Children and the Social and Religious Opposition faced by them

## DISCUSSION:

To curb the ever rising burden of Thalassemia and other hemoglobinopathies national and regional prevention programs play an essential role [17]. A similar role is being performed by the Punjab Thalassemia Prevention Project since 2012. It has the four critical elements of a population-screening program defined by Thalassemia International Federation which are: education of all stakeholders, use of standardized methods of carrier screening, the availability of genetic counseling and genetic diagnostic services, and PND [18]. We aimed to get a diversified sample from an extensive geographical area in comparison to the few KAP studies conducted previously [19, 20, 21]. To the best of our knowledge this is the only study in Pakistan which has tried to gauge the social and religious opposition that parents have to face with regards to prenatal diagnosis and termination of affected fetus.

Similar to previously conducted studies in Pakistan, majority of the parents interviewed had consanguineous marriage (77%), low level of literacy (23% had no schooling at all) and low income (79% had income below 150 USD). Despite this, 83.5% of them had an adequate knowledge about Thalassemia, its genetics and treatment. This is in contrast to a 2016 study assessing parental awareness in which 60% of the respondents were completely unaware about the disease [22]. Majority (86%) were well aware about PND and its importance in disease prevention, compared to 36% in a previous KAP survey conducted in Karachi [21].A study in Iran showed 7% had poor and 62% of parents had a mediocre level of knowledge [23].When the attitudes of the parents in our study were assessed, 95% agreed on opting for PND in a future pregnancy and 93% agreed on termination if the fetus turns out to be affected. No schooling was associated with inadequate knowledge and negative attitudes implying the importance of education. The adequacy of knowledge correlated with the development of positive attitudes ($p = 0.00$). Thus better the knowledge imparted to the caregivers, the more positive their attitudes were towards disease prevention. When compared with a similar study conducted in Kolkata, India [24] the overall knowledge (83.5% vs 57.9%) and attitudes (98.4% vs 83.8%) of our parents were better. The difference in knowledge and attitude of our respondents was most likely because they had already been sensitized by the genetic counselors when they availed testing facilities at PTPP. As Shehzad et al has pointed out in his survey that genetic counseling received at Thalassemia centers resulted in improved awareness among parents [19]. Similarly, a study in Syria also found improvement of knowledge and skill scores among caregivers when they were given a teaching guide which in turn led to improvement in quality of life [25].

93% of individuals who had an upcoming pregnancy, after

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diagnosis of Thalassemia in family, opted for prenatal diagnosis when compared to 42% in KAP survey in Islamabad/Rawalpindi [19] and39% in a 2012 study[26]. Among these individuals 12% faced opposition from their family members when they went for diagnostic testing and this opposition rose to 20% when they had to opt for termination. The local religious clerics opposed PND in 3% of the cases and termination in 7% of the cases. Despite this 91% of the respondents demonstrated good practice with regards to termination. In contrast KAP survey in Karachi [21]reported that 76.6% parents didn't opt for CVS and didn't know when to opt for TOP. The factors resulting in low PND in our country including low utilization of services, lack of awareness, poor access, delay in seeking advice and high cost [27] were not limiting factors for our respondents. Despite the official ruling from religious scholars regarding TOP before 16 weeks of pregnancy many people will find it difficult to opt for termination since Muslims believe that any calamity (in this case the birth of an affected child) is Allah's will and should be accepted. This religious dilemma is not only confined to Pakistan, but Muslims and other religious communities elsewhere in the world [28]. The religious dilemmas along with social stigmas and cultural pressures prove to be a hindrance for effective prevention. It is therefore important that prevention programs take on board religious scholars and influential community people to help build a rapport with masses and address these issues hindering effective prevention. The main limitation of this study is that instead of hiring third party interviewers, PTPP staff themselves conducted the interviewers which may lead to interviewer bias. Furthermore outcome analysis regarding the number of individuals who opted for termination despite religious and social pressure couldn't be conducted. A practice score couldn't be effectively devised as only 4 questions were there to determine good practices. Further studies in this direction would be fruitful.

## CONCLUSION

The study concludes that the awareness and genetic counseling services imparted by population screening programs have a positive impact on the knowledge, attitudes and practices of the caregivers of Thalassemia patients. Such programs should be conducted on national level, and generate effective policies to minimize religious and social opposition. Only then can effective prevention practices be implemented and the disease burden reduced.

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