

# Evaluation of Factors Affecting Awareness About Beta-Thalassemia in Western Rajasthan

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## ABSTRACT

**Aims:** To determine the factors influencing awareness about beta-thalassemia in the population. **Settings and Design:** A cross sectional study was conducted by the Department of Pathology, AIIMS, Jodhpur. **Methods and Material:** The study population included participants with medical as well as non-medical background, to ensure representation of all sections of the society. Data was collected in an objective survey form drafted in simple language. **Statistical Analysis Used:** The data was analysed using Microsoft Excel and Chi Square Test for Independence was performed. **Results:** The participants with a positive family history had significantly more knowledge compared to others, but even these participants didn't have complete knowledge about the disease. Age and gender had no significant impact on the results. The mode of occurrence of beta-thalassemia was known to less than half of the participants, with even less number being aware of the fact that diagnosis of beta-thalassemia can be made before birth. Participants with a medical background were aware that there were several forms of beta-thalassemia, but the knowledge about treatment options was limited. **Conclusions:** Various factors affect the awareness in the general population, which has an effect on the outcome of screening programmes. There is a need for successful implementation of a screening programme for beta-thalassemia in order to reduce the financial burden that it imposes on healthcare facilities and to lessen the emotional burden on relatives of patients with the disease.

**Keywords:** Anaemia, beta-thalassemia, screening

## Introduction

Beta thalassemia, a highly prevalent medical disorder in western Rajasthan, is one of the most common genetically transmitted diseases. The annual occurrence of conceptions with beta-thalassemia in the world is more than 42,000<sup>[1]</sup> with around 10,000 affected children born in India every year.<sup>[2]</sup> It is a major public health problem in India.

Despite being classified as a potentially preventable disease, many new cases are diagnosed every year. As per Indian data, the overall prevalence of beta-thalassemia trait is 2.78% and varies from 1.48% to 3.64% in different states.<sup>[3]</sup> India has a high prevalence of hemoglobinopathies and there are very few articles in Indian literature about factors affecting awareness about the disease.

Developed countries like United States of America, Australia, New Zealand, and many countries of Europe offer prenatal screening as a routine practice. Many countries with at-risk populations, like Greece, Cyprus, and Iran have successfully reduced the incidence by implementing preventive measures through national policies.<sup>[4]</sup> However, in most of the developing countries, there are no nationally coordinated programs for the

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same. India needs a national program for the prevention and control of thalassemia.<sup>[5]</sup>

Screening programs form the corner stone in the strategy against such genetically transmitted diseases, and various types of screening like population screening, mass awareness program, antenatal screening, premarital screening, cascade screening, and students' screening can be utilized for creating awareness about the disease.

Apart from professional input, the success of the screening program being utilized depends on the awareness about the disease in question in the population being screened. Various factors may affect the awareness about thalassemia in the general population and these factors have an effect on the outcome of the screening program.

The study and determination of these factors will help in the successful implementation of a much-needed screening program for beta-thalassemia in the region. The main aim of the study was to determine the factors influencing awareness about beta-thalassemia in the population.

## Materials and Methods

A cross-sectional study was conducted at a tertiary care hospital in Jodhpur after obtaining the required ethical clearance dated 19-12-2017. The study population included family members of individuals diagnosed with thalassemia, patients visiting the hospital for other ailments, technical and administrative staff, medical students, and doctors. This was done to ensure representation of all sections of society in the study.

Data was collected in an objective survey form drafted in simple language, available in English and Hindi. Statistical analysis was performed using SPSS software and a *P* value of  $< 0.05$  was considered as significant.

DEMOGRAPHIC DETAILS	
No. of respondents	1210
Demographic Profile	Participants
Gender	
Male	538
Female	672
Mean Age in years (range)	33.6 (17-72)
Education	
Less than graduation	395
Graduate	815
Family History	
Yes	59
No	1151

Figure 1: Summary of demographic details

## Result

Overall, 1210 participants took part in the survey, out of which 538 (44.5%) were males and 672 (55.5%) were females. The age of the participants ranged from 17 to 72 years, with an education level of 815 of them being graduation and above; 59 of the participants had family member with beta-thalassemia. The demographic details are summarized in Figure 1.

Five hundred twenty-four respondents knew the correct causative factor for thalassemia, i.e., genetic transmission. Four hundred forty-three participants responded that the diagnosis of thalassemia could be made before birth. Two hundred thirty-five participants were aware that there was more than one form of thalassemia. Two hundred forty-three of the respondents knew that there were treatment options available for thalassemia.

Evaluation by gender [Figure 2] showed that 41.4% males and 44.8% females were aware that thalassemia was caused by genetic transmission. 35.1% of males and 37.7% of females responded that the diagnosis of thalassemia could be made before birth. Only 21.6% of males and 17.7% of females were aware that there was more than one form of thalassemia. 20.8% of males and 19.5% of females knew that there were treatment options available for thalassemia. With a *P* value of 0.274, there was no significant difference in knowledge between males and females.

The participants who were graduates and above had more awareness about thalassemia [Figure 3]. 49% of these respondents knew that thalassemia was caused by genetic transmission, 44.9% were aware that thalassemia could be detected before birth, 22.2% knew about occurrence of more than one form of the disease, and 21.6% were aware that treatment options were available for the disease.

Presence of family member affected by thalassemia had an impact on knowledge about the disease in participants [Figure 4]. 78% of these participants knew that thalassemia was caused by genetic

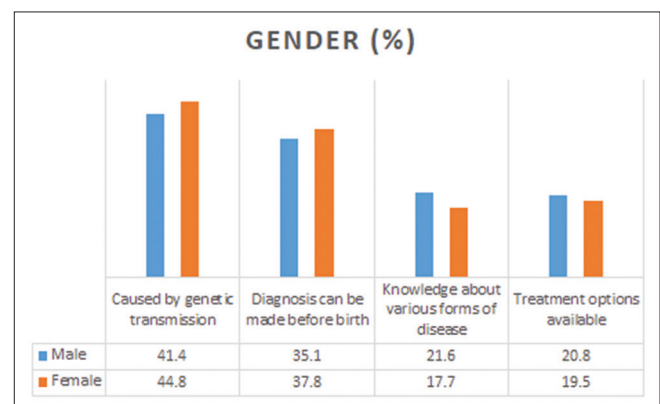
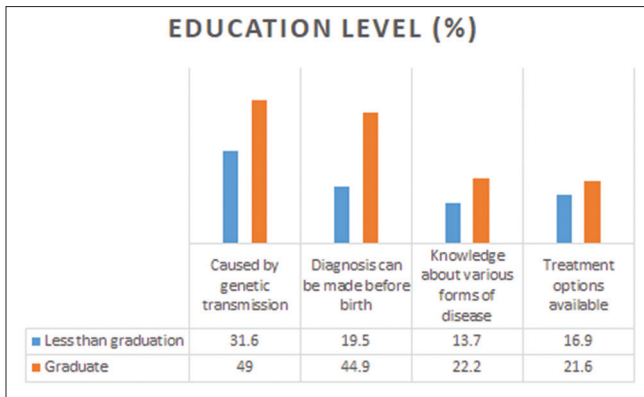


Figure 2: Bar chart showing awareness about the disease in male and female respondents



**Figure 3:** Bar chart showing variation in awareness on basis of level of education of respondents

transmission, 72.9% knew that the diagnosis of thalassemia could be made before birth, 88.1% were aware that there were various forms of the disease, and 62.7% had knowledge about the treatment options.

There was a significant difference in knowledge in respect to education level and presence of family member with thalassemia, with *P* values of 0.012 and <0.0001, respectively.

### Discussion

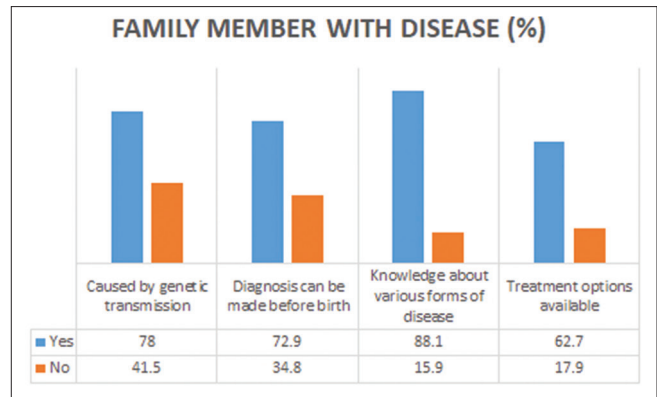
This study was a cross-sectional study exploring the factors affecting awareness about beta-thalassemia in the general population and also in family members of patients with the disease.

43.3% of the participants knew that beta-thalassemia was caused by genetic transmission. This finding was similar to those obtained by Ishaq *et al.*<sup>[6]</sup> (44.6%) and Saxena *et al.*<sup>[7]</sup> (47.5%). 36.6% of the participants were aware about the possibility of prenatal diagnosis of beta-thalassemia but only 20.1% were aware about the treatment options.

Although there was no significant difference in knowledge between males and females, there was significantly more knowledge in participants with higher education and among those who had the presence of family member with the disease.

The need for prevention of thalassemia is necessary due to its high prevalence, the financial burden that it imposes on healthcare facilities, difficulties in providing optimal treatment for patients due to overburdened healthcare facilities, and the numerous fatalities from untreated cases.<sup>[8]</sup> Due to the absence of a comprehensive national policy, there has been a lack of success in regard to screening programs.<sup>[9]</sup>

Successful screening programs in other countries have been based on appropriate education schemes for health care professionals and general population, in order to create requisite awareness among them. Information dissemination among the general



**Figure 4:** Bar chart showing effect of positive family history in respondents on the level of awareness

population can effectively be done by use of posters, information booklets, and involvement of mass media. These should include clinical features, disease course, life expectancy, associated morbidity/mortality, and available treatment options and their costs. This information should be presented in a simple manner and should be in the local language of the region. Primary care physicians play a crucial role in this regard.

Primary care physicians are usually the first point of contact for the general population with the health care system. They are more accessible, and often familiar to the patient/relatives seeking medical advice, which leads to the building of trustworthy relationship. As and when required, people are referred to specialty centers on the basis of the evaluation of their primary care physicians. They can educate and counsel the caregivers about various aspects of the disease, which will reduce the apprehension and help in building a congenial environment for the patient and the caregivers.

A survey was conducted by Radke *et al.* to determine the educational needs and knowledge among caregivers of thalassemia patients. The caregivers wanted to gain more information regarding the clinical outcomes and complications, access to well-defined care and management guidelines, and health educational materials for patients. Most of the caregivers felt that there was a lack of well-defined and coordinated care plan.<sup>[10]</sup> This aspect can be taken care of by the primary care physician.

An important aspect of awareness should be dissociation of prenatal diagnosis with social stigmatism, which is highly prevalent even among families with good educational and socioeconomic background. Introduction of formal education on thalassemia in school may help in overcoming this stigma.<sup>[11]</sup>

The most important effect of any program should be to instill appropriate knowledge among individuals/couples in order to make informed decisions regarding options available to them. This will lead to acceptance of prenatal testing which in turn will lead to a decline in the birth of children born with thalassemia.<sup>[12]</sup>

Individuals/couples are more likely to adhere to such advice if it came from a familiar primary care physician whom they trust.

Many endemic countries have set up national programs for the prevention of thalassemia, which are guided by comprehensive policies. The basis of such programs is formed by public education and awareness, screening for carriers using molecular methods, followed by genetic counselling.<sup>[4]</sup>

However, in spite of a well-organized program, the prevalence of thalassemia may not decrease in the society due to reluctance in opting for prenatal diagnosis, hesitancy to approach health care professionals, refusal to terminate affected pregnancy due to personal beliefs and, sometimes, error in prenatal diagnosis. Thus, programs should be customized to take into account the cultural and local characteristics of the population being targeted.

In the present scenario, primary care physicians hold an important responsibility for early diagnosis so that prompt management can be initiated. After the initiation of treatment, the onus of continuous management and looking after the day-to-day issues rests on the primary care physician.

Thus, in order for a large scale screening program to be successful, the strategy should aim to sensitize health care professionals and the community to the problem of thalassemia.<sup>[8]</sup>

## Conclusion

Creating awareness and educating the public regarding the disease will be cost-effective in the long run, decrease the incidence of disease in the community, and also contribute to the improvement of quality of life of patients with thalassemia. Active measures are required on part of health care professionals in order to reduce the burden of thalassemia. The primary care physicians, as a link between the general population and specialized medical care, are very important for successful implementation of such a program.

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## Conflicts of interest

There are no conflicts of interest.

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