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A Study on Awareness of Thalassemia among Pregnant Women in India

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Abstract
Purpose: *This paper aims to explore the level of awareness about thalassemia among pregnant women in Gujarat, India. It also attempts to discover the attitudes of pregnant women towards thalassemia testing and examine whether an association exists between women's age, education and income levels and their attitudes towards thalassemia.*
Design/methodology/approach: *The paper uses a quantitative methodology. Data is collected through structured interviews of 30 pregnant women taken in person by meeting respondents at hospitals and gynecologists' clinics.*
Findings: *The findings indicate a reasonably good awareness of thalassemia and an above-average level of knowledge about its screening test among pregnant women in the Indian state of Gujarat. There is a high level of willingness for women to take the screening test themselves and get their husbands to take it. The attitudes towards thalassemia testing were found to vary by age and educational qualifications of respondents, but income levels did not have any influence.*
Practical implications: *The findings of this study can help doctors understand the importance of creating awareness about thalassemia. The study shows that educational qualifications and age, but not income levels, affect pregnant women's attitudes towards thalassemia awareness and testing, thus underscoring the importance of using educational programs and tools to increase the level of awareness about thalassemia among the Indian population.*
Originality/value: *This study is one of few that offers insight into the level of awareness about thalassemia among Indian pregnant women and demonstrates the effect of factors such as age, educational qualifications and income levels on the attitudes of pregnant women towards thalassemia testing.*
Keywords: *Thalassemia, Awareness, Pregnancy, India, Screening*

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I. Introduction

Thalassemia is a rare inherited blood disorder in which the body makes an abnormal form of hemoglobin. Hemoglobin is the protein molecule in red blood cells that carries oxygen. (Holm, 2019)

Thalassemia is a hereditary disorder characterized by a decrease in the synthesis of globin chains (alpha or beta). Impaired globin chain synthesis causes impaired production of hemoglobin and eventually results in a hypochromic microcytic anemia because of defective hemoglobinization of the red blood cells (Weatherall, 2010a, 2010b).

Having thalassemia is a burden for the patient and the family. Lifelong treatment with increasing risk of comorbidity and complications over time affects a patient's mental health. An observational study has shown a higher rate of psychiatric disorders in thalassemia patients as compared to the general population (Mednick et al., 2010). Ghanizadeh (2006) found more than 43% of the thalassemia patients having recurrent thoughts of suicide and 27.3% considering suicide in the past year (Ghanizadeh, 2006).

People with thalassemia traits require no treatment or long-term monitoring. They usually do not have iron deficiency, so iron supplements will not improve their anemia (Olivieri, 1999; Rund and Rachmilewitz, 2005).

Due to socio economic problems, such as financial constraints, emotional distress, fear of social exclusion and discrimination (Ahmed et al. 2000; Samavat and Modell 2004; Saxena and Phadke 2002) people avoid considering this as a problem and thus awareness is not well developed across the globe.

In India, every year 10,000 children are born with thalassemia which accounts for approximately 10% of the total world incidence of thalassemia-affected children (Sengupta, 2007) and one in eight of thalassemia carriers live in India. The prevalence of thalassemia ranges between 0.6% and 15% across south India (Shantaram, 2016)

India has nearly 42 million carriers of the β-thalassemia trait. There are communities in which it is more prevalent such as Sindhis, Punjabis, Gujaratis, Bengalis, Mahars, Kolis, Saraswats, Lohanas, and Guard. In West Bengal and Northeastern states, specifically Hb E, a variant of hemoglobin, significantly contributes to the disease burden (Verma, Saxena and Kohli, 2011)

Lack of awareness about thalassemia can adversely affect thousands of infants. Parents who are carriers of thalassemia and are unaware about it can pass it on to their children unknowingly as it is hereditary. Lack of knowledge of symptoms may lead them to think that they are suffering from something else even if thalassemia symptoms are manifest. Creating awareness at the stage of pregnancy itself can help many or people avoid making irrational decisions. To the best of the researcher's knowledge, there is very little research on this in the Indian context and no such study for the state of Gujarat.

Therefore, this study aims to explore the level of awareness about thalassemia among pregnant women in Gujarat, India.

More specifically, the study addresses the following research questions:

RQ1: Is there awareness about thalassemia among pregnant women in the Indian state of Gujarat?

RQ2. Do pregnant women in the Indian state of Gujarat have knowledge about testing that can help early detection of thalassemia?

RQ3. What are the attitudes of pregnant women in the Indian state of Gujarat towards thalassemia testing and termination of pregnancy due to positive detection of thalassemia?

RQ4: Is there a relationship between women's age, education and income levels and their attitudes towards thalassemia testing?

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The paper is organized as follows. The next section deals with an in-depth literature review about thalassemia and its awareness among pregnant women worldwide and in India. The next section discusses the research methodology adopted. This is followed by the findings of the survey conducted among pregnant women in the Indian state of Gujarat. The conclusions from the findings are presented next. Finally, the discussion section provides the practical implications of the study, limitations and further scope for research.

II. Literature Review

Meaning and effects of Thalassemia

Thalassemia is one of the most common hereditary disorders reported in the world affecting around 1.5% of the world's population and is found in around 60,000 new symptomatic individuals being born each year (Vichinsky, 2005). A study estimates around 2.9 % of the world's adult population to be carriers of this genetic disorder (World Health Organization, 2005).

Estimates show that 3 % of the world population is heterozygous for β-thalassemia with more than 200 different mutations and each year, more than 300,000 children are born with severe β-globin disorders (Birgens and Ljung, 2007).

Thalassemias are described as inherited autosomal recessive disorders characterized by reduced rate of hemoglobin synthesis due to a defect in α or β-globin chain synthesis (Chiruka and Darbyshire, 2011). Thalassemia results in deficiency of blood (anemia) due to the destruction of red blood cells (Ghodekar et al., 2010; Caocci et al., 2012) which is due to inability of the body to produce either of the two hemoglobin proteins in red blood cells (alpha and beta) in sufficient amounts. This deficiency, causes red blood cells to become defective, rendering them unable to carry oxygen effectively around the body (Thalassemia Society of Pakistan, 2015).

According to Webster's New World Medical Dictionary (2008), a homozygous β-thalassemia patient (β-thal) is someone who is transfusion-dependent due to severe anemia caused by underproduction or absence of beta chains and hence, underproduction of hemoglobin.

Patients with thalassemia require continuous care throughout their lives (Prasomsuk et al., 2007) since there is no cure currently available. Thalassemic patients require blood transfusions at various intervals depending upon the severity of the disorder.

β-Thalassemia occurs most frequently in people of Mediterranean, Middle Eastern, Southern Asian and African ancestry. Gene frequencies of the disorder can vary between 3 and 10% depending on geographic region (Olivieri, 1999).

The most appropriate approach to deal with such diseases where no cure is currently available, is prevention (Tuzmen et al., 1996). An effective prevention program involves education, identification of carriers and reproductive counselling, as well as prenatal diagnosis (Alkuraya and Kilani, 2001). Several organizations recommend prenatal diagnosis as a means of prevention of thalassemia and other hemoglobinopathies

(American College of Obstetricians and Gynaecologists, 1993; Canadian Task Force on the Periodic Health Examination, 1994).

The main primary prevention strategy used in thalassemia endemic countries is awareness with premarital screening and genetic counselling. Screening and genetic counselling are effective in some communities, while they have little impact in others because many do not undertake screening tests for thalassemia for a variety of reasons including lack of awareness (Al-Farsi et al., 2014). Gender, education level, age, being single, and income level also contribute to unwillingness to participate in premarital screening (Al-Farsi et al., 2014). In addition, carriers sometimes refuse genetic screening or testing due to cultural reasons (Zeinalian et al., 2013) and from fear of stigmatization (Verma et al., 2011; Widayanti et al., 2011; Fahad et al., 2012). Additionally, the nature of the disease (carriers are normally healthy) and denial were additional reasons why some people do not want to be tested voluntarily for genetic conditions such as thalassemia (Garewal et al., 2005) as well as cost and difficulty of accessing the services (Saxena and Phadke, 2002).

For any screening procedure to be widely applicable, it is imperative for it to be accepted by the involved parties. In case of prenatal screening for thalassemia, acceptance is particularly crucial because the results of the screening procedure lead to decision-making issues such as terminating the pregnancy in cases of a thalassemia-affected fetus.

The level of awareness and acceptance of prenatal screening as a preventive measure for thalassemia varies from country to country, depending on the health system, religious beliefs, and cultural and educational background of the population (Alkuraya and Kilani, 2001).

Awareness about Thalassemia

Most existing research on the awareness about and acceptance of prenatal diagnostic screening has been conducted in Western countries (Lippman et al., 1985; McGovern et al., 1986; Cao et al., 1987; Spencer and Cox, 1988; Julian-Reynier et al., 1993; Hietala et al., 1995; Haddow and Palomaki, 1996) revealing a comparatively higher level of acceptance than studies conducted in Middle Eastern countries (Zahed and Bou-Dames, 1997; Zahed et al., 1999).

Parental screening is the only method to enable a couple to determine their carrier status and estimate the risk of having a Thalassemia affected pregnancy/birth (Atkin et al., 1998). However, in most countries, genetic testing is still not a common practice, and diagnoses are not made until parents are faced with serious complications. Even in the event of adverse outcomes such as stillbirth and early deaths, couples avoid genetic testing because of financial restraints, emotional distress, fear of social exclusion and discrimination (Ahmed et al., 2000; Saxena and Phadke, 2002; Samavat and Modell, 2004).

On many occasions doctors do not suggest genetic counselling to the affected Beta-Thalassemia individual, and sometimes it is the individual's preference, based on religious grounds, to avoid testing procedures (Ahmed et al., 2006; Zahed and Bou-Dames, 1997).

There are also negative different beliefs and attitudes towards termination of a fetus affected with Thalassemia major (Alkuraya and Kilani, 2001; Samavat and Modell, 2004).

Existing research shows a very low level of awareness about Thalassemia across the globe.

Gill and Modell (1998) found a low level of awareness about Thalassemia in Pakistan. Some of the reasons attributed to the lack of awareness are societal factors, literacy rate, cultural boundaries and religious preferences. Chattopadhyay (2006) found that lack of awareness is a major barrier to prevention and disclosure of the disease.

Another study by Ahmed et. al. (2000) in Pakistan demonstrated the feasibility and acceptance of creating awareness about prenatal diagnosis in a Muslim country such as Pakistan through the involvement of religious leaders. A ruling by two renowned Islamic scholars about the religious validity of terminating a pregnancy if the fetus is affected by a serious genetic disorder led to 300 couples opting for prenatal screening in the first three and a half years of the screening program. The non-utilization of prenatal diagnosis was found to be mainly due to the cost of the test and fear of undergoing the test (Ahmed et. al., 2000).

Some studies revealed a rejection of prenatal diagnosis among Muslim population in Lebanon linked to their rejection of abortion due to religious beliefs (Zahed and Bou-Dames, 1997; Zahed et. al., 1999).

Awareness about Thalassemia in Pregnancy in India

While Thalassemia is receiving increasing attention in India, its prevention continues to be difficult despite efforts of public health professionals and the government. Chattopadhyay (2006) found lack of access, low awareness, low-risk perception and poverty to be constraints to the prenatal screening of Thalassemia.

In India, socio-cultural beliefs that render carriers of Thalassemia to be unsuitable marriage partners also prevent young women and their parents from participating actively in screening programs (Chattopadhyay, 2006).

Thus, the existing literature shows a low level of awareness about Thalassemia and several socio-cultural barriers to screening in India. To the best of the researcher's knowledge, there is no such study for the

state of Gujarat. Hence, this study aims to address the gap in the existing research and explore the level of awareness about thalassemia among pregnant women and their attitudes to its screening in Gujarat, India.

III. Research Methodology

As mentioned earlier, this research paper deals with the following research questions:

RQ1: Is there awareness about thalassemia among pregnant women in the Indian state of Gujarat?

RQ2. Do pregnant women in the Indian state of Gujarat have knowledge about testing that can help early detection of thalassemia?

RQ3. What are the attitudes of pregnant women in the Indian state of Gujarat towards thalassemia testing and termination of pregnancy due to positive detection of thalassemia?

RQ4: Is there a relationship between women's age, education and income levels and their attitudes towards thalassemia testing?

A survey of pregnant women in the state of Gujarat was carried out to answer these research questions by visiting various hospitals and gynecologists' clinics. The sample size for the survey was 30. The research instrument for the surveys was a structured interview with a combination of open and close-ended questions that were taken in person by meeting pregnant women patients at hospitals and gynecologists' clinics. The sampling method used was convenience sampling, where pregnant women were approached based on permission received by the researcher from hospital administrators and doctors.

IV. Findings

This section presents the findings of the survey conducted among pregnant women. The initial tables deal with the composition of the sample for the survey, followed by descriptive data about the questions asked to pregnant women and finally, the relationship between women's awareness of thalassemia and attitudes towards testing on one hand and their demographic factors on the other.

Table 1: Sample Composition: Weeks into Pregnancy

Weeks into Pregnancy	**Percentage of Respondents**
0 - 4 weeks	26.5
5 weeks - 8 weeks	32.4
9 weeks - 12 weeks	14.7
13 weeks - 16 weeks	5.9
17 weeks - 20 weeks	5.9
21 weeks - 24 weeks	2.9
25 weeks - 28 weeks	2.9
29 weeks - 32 weeks	5.9
33 weeks - 36 weeks	2.9
Total	**100.0**

The majority of the respondents (32.4%) of the survey were between 5-8 weeks of their pregnancy, followed by women in early pregnancy (26.5%) and women who were 9-12 weeks into their pregnancy (14.7%).

Table 2: Sample Composition: Number of Siblings

Number of Siblings	**Percentage of Respondents**
0	29.4
1	17.6
2	35.3
3	14.7
4	2.9
Total	100.6

Most of the respondents had two siblings (35.3%), and a very small component (2.9%) had four siblings.

Table 3: Sample Composition: Existence of Children

Existence of Children	**Percentage of Respondents**
No	85.3
Yes	14.7
Total	100.0

Most of the respondents (85.3%) were going to be parents for the first time.

Table 4: Sample Composition: Educational Qualification

Education Qualification	Percentage of Respondents
Below Primary Education	4.5
10th Grade	0.0
12th Grade	13.6
Graduation	50.0
Post-Graduation	22.7
Professional	9.1
Total	100.0

Out of the sample, half (50%) of the respondents have finished graduation, and only a few (9.1%) are professionals.

Table 5: Awareness About Thalassemia

Level of Awareness	Percentage of Respondents
Maybe but not exactly	2.9
No	17.6
Yes	79.4
Total	**100.0**

The majority of the respondents were aware of the blood disease thalassemia (79.4%) followed by those who were not aware. A very small percentage (2.9%) were not sure about their own knowledge of the disease.

Table 6: Family History of Blood Disorder or Blood Transfusion (including grandparents, siblings, children)

Family History	Percentage of Respondents
No	94.1
Yes	5.9
Total	100.0

Of the total respondents, most of the respondents (94.1%) did not have anybody in the family that suffered from blood disorders or required regular transfusions.

Table 7: Family Diagnosis of Blood Disorder

Knowledge of diagnosis of Blood Disorder	Percentage of Respondents
No	88.2
Yes	11.8
Total	100.0

Out of the total percentage of respondents, the majority of them (88.2%) did not have anyone diagnosed with blood disorders in their family.

Table 8: Marriage Within the Family

Marriage within the family	Percentage of Respondents
No	94.1
Yes	5.9
Total	100.0

Almost 94.1% of the respondents were not married within the same family.

Table 9: Awareness About Screening Test

Level of Awareness	Percentage of Respondents
Maybe but not exactly	2.9
No	17.6
Yes	79.4
Total	100.0

The test to detect the blood disorder thalassemia was known to a majority of the respondents (79.4%) suffering from the disease, whereas a few of them (2.9%) were not really sure what it was exactly.

Table 10: Objection to Taking Screening Test

Objection to Test	Percentage of Respondents
No	82.4
Yes	17.6
Total	100.0

The majority of the respondents (82.4%) did not have any problem taking the test; therefore they were willing to go for the screening test.

Table 11: Objection to Testing of Husband

Objection to Husband's Testing	Percentage of Respondents
No	61.8
Yes	38.2
Total	100.0

The majority of the respondents (61.8%) did not mind taking the screening test.

Table 12: Preference for Abortion Post Positive Testing

Preference	Percentage of Respondents
Abortion	32.4
No Abortion	67.6
Total	100.0

If the child turns out to be diagnosed with a blood disorder many of the respondents (67.6%) were still not prepared to go for an abortion and were strongly against getting an abortion.

Table 13: Plan for Another Child Post Abortion

Plan for Another Child	Percentage of Respondents
Maybe	17.6
No	38.2
Yes	44.1
Total	100.0

The majority would give it a try (44.1 %) again but a handful of them (17.6%) were still not sure if they should go through the whole process again and take a risk.

Table 14: History of Spontaneous Abortion or Unexplained Child Death

History	Percentage of Respondents
No	97.1
Yes	2.9
Total	100.0

The majority of the respondents (97.1%) had not faced an abortion before but a small percentage (2.9%) of the respondents had gone through that process in the past.

Table 15: Cross Tabulation of Age of Respondents with History of Spontaneous Abortion of Unexplained Child Death

Have you ever had a spontaneous abortion or has your child died of undiagnosed diseases	Age			
	19-23	**24-29**	**30-34**	**Total**
No	26.5	44.1	26.5	97.1
Yes	0.0	0.0	2.9	2.9

Total	26.5	44.1	29.4	100.0

None of the respondents in the age group of 19-23 and 24-29 years had undergone a spontaneous abortion or had a child die of undiagnosed disease. In the age group of 30-34 years, only a small percentage (2.9%) had experienced the spontaneous abortion process before.

Table 16: Cross Tabulation of Age of Respondents with Willingness for Testing of Husband

If the results show that you have Thalassemia minor/major would you mind getting your husband tested?	**19-23 years**	**24-29 years**	**30-34 years**	**Total**
No	17.6	26.5	17.6	61.8
Yes	8.8	17.6	11.8	38.2
Total	26.5	44.1	29.4	100.0

Between the age group 19-23 years and 30-34 years, the same number of respondents (17.6%) don't mind getting their husbands tested. The majority of the respondents (61.8%) don't mind getting their husbands tested. In the age group of 24-29 years, this proportion was higher at 26.5%.

Table 17: Cross Tabulation of Educational Qualifications of Respondents with Awareness About Thalassemia

Do you know about the blood disease (Thalassemia)	Below Primary Education	10th Grade	12th Grade	Graduation	Post Graduation	Professional	**Total**
Maybe but not exactly	4.5	0.0	0.0	0.0	0.0	0.0	4.5
No	13.6	0.0	4.5	4.5	0.0	0.0	22.7
Yes	0.0	9.1	13.6	13.6	22.7	13.6	72.7
Total	18.2	9.1	18.2	18.2	22.7	13.6	100.0

Out of the entire sample, 72.7%, irrespective of educational qualifications, are aware of the existence of the blood disease thalassemia. Going in-depth, the respondents with a lower level of education (below primary education) (13.6%) do not know about the blood disease thalassemia. The disease is most known to the respondents who have completed post-graduation (22.7%).

Table 18: Cross Tabulation of Educational Qualifications of Respondents with Family Diagnosis of Blood Disorder

If yes, did they know the diagnosis? (this includes grandparents, siblings, children)	Below Primary Education	10th Grade	12th Grade	Graduation	Post Graduation	Professional	**Total**
No	18.2	9.1	18.2	18.2	9.1	13.6	86.4
Yes	0.0	0.0	0.0	0.0	4.5	9.1	13.6
Total	18.2	9.1	18.2	18.2	13.6	22.7	100.0

The majority of the respondents (84%) did not know the diagnosis, and it was mostly unknown among those with education below primary level, 10th Grade and 12th Grade (18.2%).

Table 19: Cross Tabulation of Family Income of Respondents with Objection to Screening Test

Do you mind taking a screening test?	0 - 3,00,000	3,00,001 - 5,00,000	5,00,001 - 10,00,000	10,00,001 and Above	**Total**
No	50	20	10	10	90
Yes	0	0	10	0	10
Total	50	20	20	10	100

The majority of all income group respondents (90%) don't mind taking the test. Even at the lowest income range of Rs. 0-300,000, all the respondents do not mind taking the test.

V. Discussion

The findings of this research study indicate a reasonably good awareness of thalassemia among pregnant women in the Indian state of Gujarat. There is also an above-average level of knowledge about the screening test that can help early detection of thalassemia.

More than three-fourths of the respondents had no objection to taking the screening test themselves and were also convinced about the willingness of their husbands to take the screening test.

Only around one-third of the respondents were willing to go in for an abortion if they tested positive for thalassemia. Slightly more than this proportion were not willing to plan for another child if they had an abortion due to thalassemia.

The attitudes towards thalassemia testing varied by age of respondents. The highest proportion of respondents willing to be tested themselves or get their husbands tested for thalassemia fell in the age group of 24-29 years, followed by the age groups of 19-23 and 30-34 years.

The awareness about thalassemia varied by the educational qualifications of the respondents. The highest level of awareness was found among women who had completed post-graduation while the lowest level of awareness was found among the respondents with lower levels of education (below primary education).

Income levels did not play any role in respondents' willingness to get tested for thalassemia. Irrespective of income levels, 90 percent of the respondents, including those from lower-income groups, did not object to the screening test.

Limitations

The study has some limitations. The sample size is small, and the results may not be generalized to a larger population. Additionally, the respondents were from the state of Gujarat in India, and their views may not be the same as those of pregnant women in other Indian cities. There may be a bias related to the sampling method. The sample was non-random and focused on those pregnant women who visited certain hospitals and gynecologists' clinics. It is possible that respondents obtaining regular medical care during their pregnancy would be more positive in their answers towards awareness about thalassemia.

Scope for Future Research

Future research could compare the awareness levels of pregnant women in cities to those in rural areas. It would also be interesting to compare the attitudes of pregnant women towards thalassemia across various states in India.

Implications

The findings of this study make several contributions to the existing literature on awareness about thalassemia. First, it offers insight into the level of awareness about a serious condition among Indian pregnant women, addressing the dearth of such studies in the existing literature. Secondly, this study attempts to find out the effect of factors such as age, educational qualifications and income levels on the attitudes of pregnant women towards thalassemia testing.

In terms of practical implications, the findings of this study can help doctors understand the importance of creating awareness about a serious condition such as thalassemia. This is especially important for India which has a large population that is either uneducated or has lower levels of education. This study shows how educational qualifications and age, but not income levels, affect the attitudes of pregnant women towards thalassemia awareness and testing, thus underscoring the importance of using educational programs and tools to increase the level of awareness about thalassemia among the Indian population.

VI. Conclusion

This quantitative study investigates the level of awareness about thalassemia, its screening test and the required course of action after positive testing. It examines the willingness of pregnant Indian women to get tested for thalassemia themselves, get their husbands tested for thalassemia, obtain an abortion post positive testing of thalassemia and plan for another child post such abortion. The study also examines the effect of women's age, educational qualifications and income levels on their attitudes towards thalassemia, and reveals a positive relationship between the educational qualifications and awareness about thalassemia and its treatment.

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