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# Family planning practices in couples with children affected by $\beta$ -thalassemia major and its relationship with their education: An epidemiological study

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## Abstract:

**BACKGROUND:** Although prevention the birth of children with  $\beta$ -thalassemia major ( $\beta$ -TM) is an important health issue, it is rarely explored. With this background, the study was designed to find family planning practices and related factors of couples with children affected by  $\beta$ -TM.

**MATERIALS AND METHODS:** This was a cross-sectional, observational study, conducted among 324 parents with children affected by  $\beta$ -TM attending a tertiary care health facility in Eastern India. Data were analyzed using univariate and multivariable logistic regression using SPSS.

**RESULTS:** Of 324 parents, 89.5% were sexually active, 44.8% of which were currently using family planning method to prevent the birth of another child with the oral contraceptive pill most preferred (46.9%) followed by tubectomy (33.9%). Those who were sexually active, but not desirous of a child were 223, of which 41.7% had the unmet need for family planning with religious belief (41.9%) being the most predominant reason followed by unaware of methods (26.9%). In multivariable analysis, religion, caste, per capita monthly income, mothers' education level, and working status were significant predictors of unmet need for family planning adjusted with others.

**CONCLUSIONS:** Burden of unmet need for family planning among the study population was alarmingly high. Parents of the thalassaemic children should be counseled in easily comprehensible local language to increase the rate of contraception among them.

## Keywords:

Contraceptive prevalence, religion, thalassemia, unmet need for family planning

## Introduction

Thalassemia is the most common genetic disorder, affecting a large proportion of the world's population.<sup>[1]</sup> There are about 240 million carriers of  $\beta$ -thalassemia gene worldwide, which is around 1.5% of world population. It is estimated that every year over 100,000 children are born with  $\beta$ -thalassemia, of which 90% occur in low- and middle-income countries.<sup>[2-5]</sup> India is a known hotspot for thalassemi-

asemia with over 30–40 million carriers and 12,000 infants (10% of the world) being born every year with  $\beta$ -thalassemia major ( $\beta$ -TM), which implies that in every 44 min one child is born with this potentially fatal genetic disease.<sup>[6-8]</sup>

The need for the prevention of thalassemia is evident due to the high frequency of the condition and it is cost effective compared to provision of optimal treatment, as shown in previous studies.<sup>[9,10]</sup> Using appropriate family planning methods in couples who are carriers of thalassemia (i.e., parents of

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the thalassemic children) are one of the main preventive strategies along with premarital genetic counseling and antenatal screening. However, prior studies in this regard reported that despite having no desire for another child, there is high unmet need for family planning among parents of thalassemic children related to various factors such as education, religion, and economic status.<sup>[11,12]</sup>

As we know from our search, there is no prior study which explored this topic in India despite being crucial for thalassemia prevention in the country. With this background, the current study was designed to explore family planning practices and its related factors among couples with children affected by  $\beta$ -TM. The study will also quantify strength of association of various factors with unmet need of family planning unlike prior studies in the topic which only explored significant-related factors ignoring their strength of association with the unmet need of family planning.<sup>[11,12]</sup> Thus, the findings of the study will help policy makers of thalassemia burdened countries to design and prioritize interventions to meet unmet need for family planning of couples with children affected by  $\beta$ -TM to avert birth of a thalassemic.

## Materials and Methods

The study was an observational study with cross-sectional design. The study was conducted among 324 parents with children affected by  $\beta$ -TM. Our method for data collection was a structured schedule by face-to-face interview in a thalassemia outpatient department of a Medical College of West Bengal, India, from May 2016 to April 2017.

The questionnaire consisted of sociodemography (age, education, residence, type of family, religion, and caste), socioeconomy (working status, per capita monthly income), and family planning (sexually active or not, using contraceptive methods and if they did not, and the reason for it).

Parents of  $\beta$ -TM children who had visited thalassemia outpatient department during the study and consented to participate were included in the study, while parents of critically ill  $\beta$ -TM children were excluded from the study. One day in a week was arranged for data collection. On an average, thalassemia unit outpatient department gave services to 15–20  $\beta$ -TM patients on a day. An interview took on an average 15–20 min. On an average, eight parents could be interviewed on a weekly basis. Total 41 days were available for data collection (excluding public holidays). Our data collection with this method, took 1 year. Out of 328 parents interviewed, family planning-related data were missing for four parents, and hence, they were excluded from the analysis.

Data were analyzed using IBM SPSS (Chicago, USA) (version 16). Univariate and multivariate logistic regression tests were done to find out any relationship between unmet need for family planning and its various determinants. Minimum acceptable confidence level was  $\alpha = 0.05$  for all statistics and maximum acceptable significance level was  $P < 0.05$ .

Ethical clearance of the Institutional Ethics Committee of respective medical college was taken before conducting the study. Informed written consent of each study participant was taken before their participation. During data collection, their confidentiality was assured.

## Results

Majority of the parents interviewed were mothers (75.9%) with a mean age of 29.8 years, and the rest were fathers (24.1%) with a mean age of 34.8 years of the thalassemic children. The mean per capita monthly family income was 23.1 USD (range, 6.2–70.2 USD) [Table 1].

All of the study patients had received genetic counseling at the time of diagnosis of the disease in their children, but only 47.6% of them knew about hereditary nature of the disease with only 52.4% and 50.9% knew about premarital counseling and antenatal screening, respectively. Out of 223 parents, who were sexually active but not desirous of a child, 41.7% had an unmet need for family planning with religious belief (41.9%) being the most predominant reason for the unmet need for family planning [Table 2].

In multivariable analysis, significant predictors of unmet need for family planning were religion, caste, mothers' educational level, mothers' working status and per capita monthly income adjusted with age of both parents, fathers' education level, residence, and the type of family. Overall, the model was explaining 25.2% variability of outcome variable with a predictive accuracy rate of 72.6%, while Hosmer Lemeshow  $P = 0.252$  indicating model fit [Table 3].

## Discussion

The study had explored family planning practices and related factors of couples with  $\beta$ -TM children. In the present study, among sexually active couples, 44.8% were currently using family planning method to prevent the birth of another child, which was quite worse compared to Haghpanah *et al.*<sup>[11]</sup> (96.0%) and Ishaq *et al.*<sup>[12]</sup> (65.0%) but similar to findings of Mallik *et al.*<sup>[10]</sup> (51.8%). The difference of findings may be contributed to the consequence of community-wide education programs, as well as comprehensive screening and counseling programs operational in those counties unlike India.

**Table 1: Background characteristics of the study participants (n=324)**

Variable	n (%)
Age of the father (years), n=312*	
24-30	79 (25.3)
31-37	122 (39.2)
38-44	51 (16.3)
45-55	60 (19.2)
Age of the mother (years), n=320†	
21-27	109 (34.1)
28-34	151 (47.2)
35-41	46 (14.4)
42-46	14 (4.3)
Religion	
Hindu	194 (59.9)
Muslim	128 (39.5)
Christian	2 (0.6)
Caste	
General	170 (52.5)
Other backward class	44 (13.6)
Scheduled caste	108 (33.3)
Scheduled tribe	2 (0.6)
Place of residence	
Urban	91 (28.1)
Rural	233 (71.9)
Type of family	
Nuclear	208 (64.2)
Joint	116 (35.8)
Educational level of father	
In completed years of schooling	70 (21.6)
Illiterate (0)	64 (19.8)
Below primary (0-4)	75 (23.1)
Primary (5-7)	73 (22.5)
Middle (8-9)	42 (13.0)
Secondary and above (10-17)	
Educational level of mother	
In completed years of schooling	71 (21.9)
Illiterate (0)	61 (18.8)
Below primary (0-4)	81 (25.0)
Primary (5-7)	67 (20.7)
Middle (8-9)	44 (13.6)
Secondary and above (10-15)	
Father work for pay, n=312*	
Yes	299 (95.8)
No	13 (4.2)
Mother work for pay, n=320†	
Yes	85 (26.6)
No	235 (73.4)

\*12 fathers died, †4 mothers died

In the present study, among at risk couples (sexually active but not desirous of a child), 41.7% had an unmet need for family planning which was alarmingly high compared to national figures as reported in National Family Health Survey-4<sup>[13]</sup> (12.9%). Religious belief (41.9%) was the most predominant reason for the unmet need for family planning and religion emerged as a significant predictor of unmet need which may be

**Table 2: Distribution study participants according to their family planning practices (n=324)**

Variable	n (%)
Are you currently sexually active with your spouse?, n=324	
Yes	290 (89.5)
No	34 (10.5)
Reason for not currently being sexually active with the spouse, n=34	
Mother died	4 (11.7)
Father died	12 (35.4)
Not living together	18 (52.9)
If currently sexually active with your spouse then are you using any contraception?, n=290	
Yes	130 (44.8)
No	160 (55.2)
Contraception currently used, n=130	
Tubectomy	44 (33.9)
Oral contraceptive pill	61 (46.9)
Condom	25 (19.2)
Reason for not using any contraception, n=160	
Pregnant	24 (15.0)
Wish another child	41 (25.6)
Religious belief	39 (24.4)
Unaware of methods	25 (15.6)
Partner not agreeing to use	13 (8.1)
Need not felt	10 (6.2)
Fear of side effects	6 (3.8)
Menopause attained	2 (1.3)

due to Muslim preponderance in the study compared to the countries' demographic norms.<sup>[14]</sup> Lack of knowledge (26.9%) was the second-most predominant reason of unmet need in the present study. In a qualitative study by Shahraki-Vahed *et al.*<sup>[15]</sup> conducted among parents of thalassemic children, one of the study participants stated "We did not do a single thing about contraception because we did not know our disease..." which supports our findings and indicates seriousness of the situation. On the other hand, mothers' and fathers' educational level emerged as significant predictors of unmet need which may be the possible explanation for their lack of knowledge.

In this study, those who were residing in a rural area had a significantly higher unmet need for family planning. The possible explanation could be the more easy accessibility of family planning services in cities, the desire for more children in rural areas, and the higher educational level in urban areas compared to rural and remote areas. On the other hand, mothers who were not working had more unmet need which may be due to lack of financial independence which indirectly influenced her power of decision-making regarding contraceptive use. In this study, per capita monthly income emerged as one of the vital predictors of unmet need for family planning which was in concordance with the results of

**Table 3: Univariate and multivariable logistic regression analysis showing sociodemographic and socioeconomic predictors of unmet need for family planning (n=223)**

Variables	Unmet need for family planning (yes 93; 41.7%)	OR (95% CI)	P	Adjusted OR (95% CI)	P
Age of the father (increasing)	-	0.98 (0.95-1.02)	0.501	0.96 (0.87-1.07)	0.478
Age of the mother (increasing)	-	0.99 (0.94-1.04)	0.793	1.04 (0.91-1.19)	0.537
Religion					
Muslim	48 (51.6)	2.08 (1.21-3.60)	0.008	3.75 (1.69-8.31)	0.001
Hindu/Christian	45 (48.4)	Reference		Reference	
Caste					
SC/ST	33 (35.5)	1.13 (0.64-1.95)	0.709	2.63 (1.14-6.08)	0.024
OBC/General	60 (64.5)	Reference		Reference	
Place of residence					
Rural	75 (80.6)	1.91 (1.02-3.62)	0.044	1.87 (0.90-3.68)	0.098
Urban	18 (19.4)	Reference		Reference	
Type of family					
Joint	38 (46.9)	1.39 (0.81-2.43)	0.234	1.35 (0.72-2.56)	0.348
Nuclear	55 (38.7)	Reference		Reference	
Fathers educational level					
Primary and below	52 (55.9)	1.90 (1.11-3.26)	0.019	1.84 (0.97-3.48)	0.061
Above primary	41 (44.1)	Reference		Reference	
Mothers educational level					
Primary and below	52 (55.9)	2.66 (1.53-4.61)	<0.001	2.40 (1.27-4.56)	0.007
Above primary	41 (44.1)	Reference		Reference	
Mother work for pay					
No	78 (83.9)	1.99 (1.02-3.90)	0.045	3.19 (1.45-7.01)	0.004
Yes	15 (16.1)	Reference		Reference	
Per capita monthly income, USD (median 19.8)					
≤ 19.8	47 (50.5)	1.80 (1.05-3.10)	0.033	2.53 (1.30-4.92)	0.006
>19.8	46 (49.5)	Reference		Reference	

OR=Odds ratio, CI=Confidence interval, OBC/General=Other Backward Caste/General, SC/ST=Scheduled Caste/Scheduled Tribe

Haghpahanah *et al.*<sup>[11]</sup> which recommended it to be focused on while designing interventions.

As for limitations of the study, all data were self-reported, and hence, there may be under or over reporting and chances of social desirability bias cannot be overlooked. There may be specific other factors (i.e., knowledge of contraception) influencing family planning practices which we did not examine.

## Conclusion

Unmet need for family planning is alarmingly high in the study population which warrants through and prompt intervention. Parents of the thalassemic children should be regularly counseled at every given opportunity at easily comprehensible native language regarding the importance of adopting a suitable contraceptive method for either terminating or spacing childbirth. On the other hand, those who are desirous of a child should be encouraged to undergo antenatal screening to prevent birth of a thalassemic child.

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## Conflicts of interest

There are no conflicts of interest.

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