



# Knowledge and Attitude of Young Married Women Regarding Congenital Anomalies in the Fetus: A Cross-Sectional Questionnaire-Based Study from South-Central India

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## Abstract

**Background** Although congenital anomalies are a significant cause of neonatal mortality and morbidity in both developed and developing countries, middle- and low-income countries, including India, account for approximately 95% of all children born with congenital anomalies. Some birth defects/congenital anomalies are preventable, if their risk factors are modified. Young married women must have a good knowledge regarding these preventable risk factors because this is the population who will be bearing children in the near future. Therefore, this study aims to determine the knowledge and attitude of young married women regarding congenital anomalies/ birth defects, their risk factors, preventive measures, and treatment options available.

**Materials and Methods** An analytical cross-sectional study was conducted in a tertiary care center in South-Central, India, for over 1 year. Five hundred young married women (range: 18–30 years) answered a questionnaire, mainly focusing on what are birth defects, what are their risk factors and preventive strategies against them. It also included questions on how birth defects are diagnosed, and if carrying a baby with birth defects, what they would do for their management and also their knowledge regarding fetal medicine centers and fetal medicine specialists.

**Results** The mean knowledge score of the study participants was  $18 \pm 4.08$  (range: 8–27). About 82.8% of the study participants had average knowledge regarding birth defects, and only 17.2% had good and adequate knowledge scores. The knowledge regarding risk factors is grossly inadequate. The knowledge regarding advanced maternal age, maternal obesity, and consanguinity as risk factors for congenital anomalies was deficient in more than 50% of the study population. The mean attitude score was  $4.42 \pm 0.985$  (range: 1–7), indicating overall positive attitudes.

## Keywords

- birth defects
- congenital anomalies
- knowledge and attitude
- young married women

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**Conclusion** Knowledge regarding birth defects, their risk factors, and preventive strategies was moderate in the majority of the study participants. Education has some bearing on the knowledge and attitude, but the knowledge base still seems to be influenced by religious beliefs. Awareness campaigns to increase the knowledge about preventable causes of birth defects and their management strategies are urgently needed in this region.

## Introduction

The World Health Organization defines congenital anomalies (CAs) as birth defects, which can be structural or functional abnormalities, including metabolic disorders, present from birth.<sup>1</sup> Although CAs are a significant cause of neonatal mortality and morbidity in developed and developing countries, middle- and low-income countries, including India, account for approximately 95% of all children born with CAs.<sup>2,3</sup> CAs were the fifth most common cause of neonatal mortality in India, accounting for approximately 10% of all cases in 2010.<sup>4</sup>

Children with CAs have risk of developing lifelong physical, cognitive, emotional, and social challenges.<sup>5</sup> They have a bearing on the country's health expenditure as they would require long-term rehabilitative services.<sup>6</sup> Further, having a baby with congenital malformation has severe emotional and psychological stress on their mothers<sup>7</sup> and their future reproductive outcomes.

Although most parts of the country do have well-established screening programs for chromosomal anomalies and birth defects, but to avail them, the couple has to go to the health centers and that too at a specific gestational age in pregnancy. The scan for nuchal translucency at 11 to 14 weeks and a detailed anomaly scan at 18 to 20 weeks of gestation can identify majority of fetuses with CAs, but lack of knowledge regarding their need and availability are a major factor hindering their widespread usage in community. It is, therefore, essential to identify target groups of the population where the knowledge regarding birth defects is deficient. These should be the focus groups for educational programs regarding their prevention. As a means of primary prevention, good knowledge in women of reproductive age regarding preventable risk factors for CAs, like drugs, smoking, alcohol, consanguinity, and radiation exposure, is a must. Further, if diagnosed with a congenital abnormality in the fetus, their knowledge regarding the availability of treatment options would be beneficial in reducing the number of unindicated abortions.

Although a few studies have assessed the knowledge of pregnant women regarding CAs and birth defects,<sup>8–10</sup> there are no such studies from India. Young married women must have a good knowledge regarding the subject because they are the population who will be bearing children in the near future. Some of these might even have a fetus with a CA. Therefore, this study aims to determine the baseline knowledge and the attitude of young married women regarding

CAs/birth defects, their risk factors, preventive measures, and treatment options available for them.

## Materials and Methods

### Study Design and Sample

This analytical cross-sectional study was conducted in a tertiary care center in South-Central, India, for 1 year, after obtaining approval from the institutional ethical committee. The source population was all patients visiting the outpatient department of All India Institute of Medical Science (AIIMS) Bibinagar and allied health centers for any complaints. The study population included all young married women (18–30 years of age) who visited the outpatient department for any complaints and were willing to participate in the study. The sample size was calculated using Open Epi, Software. The primary variable was the awareness of women of the reproductive age group regarding birth defects or CAs in the fetus. Assuming the percentage of women with good and adequate knowledge has a 50% prevalence, 95% confidence interval, 5% type I error and 80% power, and a non-response rate of 10%, the sample size is around 486. It was, therefore, decided to include 500 participants. Convenience sampling was used to select the study participants.

### Study Instrument and Data Collection

The study tool used was a structured questionnaire prepared to assess the general and specific knowledge of the study population regarding birth defects. It was prepared both in English and the local language. The questionnaire's content was prepared by two subject experts and validated after modification by two experts not involved directly or indirectly in the study. The final questionnaire consisted of three parts: The first part contained questions relating to the sociodemographic profile of the study participants. The second part included three broad questions regarding knowledge, one about what are birth defects, one regarding risk factors for birth defects, and one question regarding their specific knowledge regarding birth defects consisting of seven subparts, from which the participants had to choose the best option as per their knowledge about the subject. The third part contained seven questions regarding the attitude of the women regarding birth defects. Informed consent was obtained from each of the study participants.

Respondents were asked to respond to knowledge items as either yes or no, with an additional "don't know" option. Incorrect or uncertain (don't know) responses were given a

score of zero, and correct answers were assigned a score of one. The total score for knowledge ranged from 0 to 32, with high scores indicating a better understanding of the study population regarding birth defects in the fetus. Items were evaluated for internal reliability using Cronbach's  $\alpha$ . Cronbach's  $\alpha$  coefficient for the knowledge questionnaire was 0.76, indicating internal reliability.

In the section on attitudes, scores were calculated based on the respondents' answers to each attitudinal statement, "agree," "disagree," or "undecided." Scores were calculated by averaging respondents' responses to the seven statements. Total scores ranged from zero to seven, with high scores indicating positive attitudes. The Likert scales were assessed for internal reliability using Cronbach's  $\alpha$ . Cronbach's  $\alpha$  coefficient was 0.79, indicating internal reliability.

### Statistical Analysis

All statistical calculations were done using (Statistical Package for the Social Science) SPSS 21 version (SPSS Inc., Chicago, Illinois, United States) statistical program for Microsoft Windows. Data were described in terms of range, mean  $\pm$  standard deviation, frequencies (number of cases), and relative frequencies (percentages) as appropriate. To determine whether the data were normally distributed, a Kolmogorov-Smirnov test was used. A comparison of quantitative variables between the study groups was made using the Mann-Whitney *U*-test and Kruskal-Wallis test. A probability value (*p*-value) less than 0.05 was considered statistically significant.

## Results

### Social and Demographic Characteristics

A total of 500 participants completed the questionnaire. ► **Table 1** shows the social and demographic characteristics of the study participants. The majority of study participants were in the age group between 26 and 30 years (46.8%). About 88.2% of the participants were educated, with 33.8% to graduate or postgraduate levels. About 17.4% were nulliparous, 20.4% primiparous, and the remaining multiparous. About 70% were homemakers, 10.8% professionals, and the remaining were employees in skilled and semiskilled professions.

### Knowledge

The mean knowledge score of the study participants was  $18 \pm 4.08$  (range: 8–27). About 82.8% of the study participants had average knowledge regarding birth defects, and only 17.2% had good and adequate knowledge scores. About 56.6% had knowledge above the means score, and the remaining were below it. The knowledge of the study population regarding birth defects in the fetus varied with their sociodemographic factors (► **Table 2**). The mean knowledge scores in the illiterate group were  $15.02 \pm 3.319$ , and that for graduates and postgraduates was  $18.72 \pm 3.712$ ; the difference was statistically significant. There was also a statistically significant variation in the knowledge scores across different age groups (► **Table 2**). Parity or any history of CA in

**Table 1** The sociodemographic data of the study population

Age group		No. of cases	Percentage
	<25	92	18.4
	26–30	234	46.8
	>30	174	34.8
Education level			
	Graduate/postgraduate	169	33.8
	Illiterate	59	11.8
	Primary	50	10.0
	Secondary	222	44.4
Parity			
	0	87	17.4
	1	102	20.4
	2	231	46.2
	3	67	13.4
	4	9	1.8
	5	4	0.8
Occupation			
	Professionals	54	10.8
	Skilled occupations	28	5.6
	Semiskilled occupations	46	9.2
	Unskilled occupations	24	4.8
	Housewife	348	69.6

self or the family did not significantly affect the knowledge scores.

Responses to the questionnaire on knowledge regarding birth defects, risk factors, and antenatal diagnosis are summarized in ► **Table 3**. The knowledge regarding risk factors is grossly inadequate. About 23.6% of the study population was unaware that over-the-counter medications are a risk factor for CAs in the fetus. Sixty-two percent were clueless regarding the teratogenic effects of infections or fever in pregnancy. Sixty-one and 39.8% were ignorant that a history of CA in one pregnancy or either of the parents, respectively, is a risk factor for recurrence in the subsequent pregnancy. About 46.4% of the study population was unaware of the benefits of periconceptional intake of folic acid in preventing CAs. The knowledge regarding advanced maternal age, maternal obesity, and consanguinity as risk factors for CAs was also deficient in more than 50% of the study population. More than 20% did not know that birth defects are preventable and treatable.

### Attitude

The mean attitude score was  $4.42 \pm 0.985$  (range: 1–7), indicating overall positive attitudes. The study participants' responses to the attitude questionnaire are summarized

**Table 2** Comparison of social and demographic characteristics and mean knowledge score

	<i>n</i>	Mean	SD	SE	Lower bound	Upper bound	Minimum	Maximum	F	<i>p</i> -Value
Education level:					95% confidence interval for mean					
Illiterate	59	15.02	3.319	0.432	14.15	15.88	9	21	16.221	0.001
Primary	50	16.80	3.417	0.483	15.83	17.77	12	23		
Secondary	222	18.51	4.275	0.287	17.95	19.08	8	27		
Graduate/ postgraduate	169	18.72	3.712	0.286	18.15	19.28	9	26		
Age group										
<25	92	18.02	4.528	0.472	17.08	18.96	9	27	8.55	0.0001
26–30	234	17.94	3.991	0.261	17.42	18.45	10	25		
>30	174	18.07	3.970	0.301	17.47	18.66	8	26		
Parity										
0	87	17.07	4.622	0.496	16.08	18.05	9	25	2.751	0.065
1	102	18.18	3.641	0.360	17.46	18.89	12	25		
>1	311	18.20	4.032	0.229	17.75	18.65	8	27		
Any h/o congenital anomaly in the fetus in self or family										
No	446	17.89	4.149							0.104
Yes	54	18.85	3.373							

Abbreviations: SD, standard deviation; SE, standard error.

in ► **Table 4**. Eighty-four percent of the study population was unaware that any pregnancy, including their own, is at risk of carrying a fetus with CAs. Fifty percent considered birth defects as God's wish for which nothing could be done. About 40% believed that if any CA is detected in the fetus, they would directly opt for pregnancy termination. More than 90% agreed that they would like to know about the management and prognosis of the anomaly detected and would like to see a doctor specializing in managing these. There was a statistically significant change in the attitude ( $p < 0.001$ ) with education status.

## Discussion

This study aimed to determine the baseline knowledge of young married women, of the reproductive age group, regarding CAs/birth defects in the fetus. It also assessed their specific knowledge like risk factors, preventive measures, available treatment options, and their attitude regarding the same. The data regarding knowledge of this subset of the population regarding birth defects is scarce. Although a few studies done in the past have focused on pregnant females, we could not find any studies focusing on this subset of the population.<sup>6</sup> Therefore, this study's target population was chosen to be women of the reproductive age group. In the present era of preconception care and counselling, it is imperative to ensure that a woman enters pregnancy with sound knowledge regarding the preventable complications and is also well versed with the available treatment options so that she can approach the concerned specialist timely.

This study found that the mean knowledge score of the study participants was  $18 \pm 4.08$  (range: 8–27). Only 17.2% of the study population was found to have adequate knowledge regarding birth defects; for the remaining 82.8%, the knowledge was average. Although a few similar studies done from other parts of the world have shown that more than 50% of the study population had good or satisfactory knowledge regarding the modifiable risk factors,<sup>3,8,10</sup> the knowledge regarding risk factors in this study was grossly inadequate. Our findings are in concordance with studies from other developing countries. A recent study done in Saudi Arabia found that the knowledge of pregnant women regarding teratogens or agents leading to malformations in the fetus is inadequate, and the authors even pressed that there is an urgent need for measures required to improve the same.<sup>11</sup> A poor level of awareness regarding birth defects was also reported in Nigeria, where only approximately 25% of nursing mothers had sufficient knowledge regarding these.<sup>9</sup> Several risk factors like glycemic control in diabetes, teratogenic medications, folic acid intake, and congenital infections are modifiable. If reproductive-age women are aware of risk factors, these could be avoided, leading to decreased incidence of birth defects. Awareness regarding treatment options also would lead them to fetal medicine centers, thereby improving fetal prognosis.

Using over-the-counter drugs is defined as the utilization of medicinal products by the individuals to take care of self-recognized disorders or symptoms or continuous use of a medication prescribed by a physician.<sup>12</sup> The practice of self-medication and using over-the-counter drugs is widespread in India.<sup>13</sup> The medicines used include antibiotics, analgesics, and

**Table 3** Responses to the questionnaire on knowledge regarding birth defects, their risk factors, and their antenatal diagnosis

K.1. What are birth defects/congenital anomalies?	Yes	No	Don't know
Birth defects are disease with unknown cause	76	336	88
Birth defects are a genetic disease	332	110	58
Birth defects are a disease acquired by pregnant woman following contact with a mother of congenitally malformed fetus	54	400	46
Birth defects are a disease caused by abnormal development of fetus in the womb	362	70	88
K.2 According to you which among the following are risk factors for developing congenital anomalies in the fetus?			
Alcohol	255	166	79
Smoking	288	138	74
Over the counter medications	316	118	66
Not taking folic acid in periconceptional period	156	232	112
Radiation exposure	283	102	115
Infections/fever in pregnancy	148	310	42
Advanced maternal age	182	245	73
Previous baby with congenital anomaly	141	305	54
History of congenital anomaly in the family (maternal/paternal)	279	199	22
Supernatural factors	104	330	66
Eating some forbidden food in pregnancy	176	276	48
Consanguinity/marriage among second- or third-degree relations	336	143	21
Maternal obesity	80	394	26
Solar/lunar eclipse	350	110	40
Coronavirus	46	346	108
Vaccination against coronavirus	56	344	100
Sex of the baby (male or female)	0	446	54
K.3. Please select the correct option for the following statements regarding birth defects/congenital anomalies			
Babies with any birth defect invariably die after birth	0	446	54
Birth defects always lead to lifelong disabilities like mental retardation and cosmetic deformity	109	339	52
Some birth defects are preventable	310	167	23
Some birth defects are treatable	325	133	42
Birth defects can be detected prenatally on ultrasound examination	313	105	82
Birth defects can recur in subsequent pregnancies	404	56	40
Babies detected with birth defects should be delivered in tertiary care hospital	411	60	29
K.4. Please select the correct option for the following statements regarding detection of birth defects/congenital anomalies			
Ultrasound can detect all congenital anomalies	342	118	40
Detailed scan for detection of birth defects is done at 3rd month of pregnancy	115	333	52
Detailed scan for detection of birth defects is done at 5th month of pregnancy	442	26	32
A special ultrasound is needed for the detection of cardiac abnormalities	337	91	72
First ultrasound should be done at 2nd month as soon as pregnancy is diagnosed	209	243	48

even antiepileptics. Some of these medications can be teratogenic, so this practice can be disastrous in early pregnancy. About 23.6% of the study population was unaware that over-the-counter medications are a risk factor for CAs in the fetus. Sixty-two percent were ignorant regarding the teratogenic effects of infections or fever during pregnancy. Infections like measles, mumps, rubella, toxoplasma, and cytomegalovirus

lead to only mild clinical features in the mother but can be very dangerous for the fetus, especially during the first trimester.<sup>14</sup> Good knowledge of their teratogenic effects is fundamental, especially because vaccination is also available against a few. Only if women of reproductive age are well aware of their primary prevention, they will enter pregnancy with a good immunity against these infectious diseases.

**Table 4** Responses of the study population, to the attitudinal statements regarding birth defects in the fetus

	Yes	No	Don't know
I too have a risk of having a baby with birth defect.	64 (12.8)	420 (84)	16 (3.2)
During pregnancy I would like to know whether my baby is affected by some form of congenital abnormality or birth defect?	422 (84.4)	70 (14)	8 (1.6)
If during pregnancy, a congenital anomaly/birth defect is detected in my fetus, I would directly go for pregnancy termination?	276 (55.2)	198 (39.6)	26 (5.2)
If during pregnancy, a congenital anomaly/birth defect is detected in my fetus, I would accept it as such, as God's decision and continue routine check-ups	221 (44.2)	253(50.6)	26(5.2)
If during pregnancy, a congenital anomaly/birth defect is detected in my fetus, I would look for a doctor who is expert in the relevant field (fetal medicine specialist)	468 (93.6)	26(5.2)	6(1.2)
If during pregnancy, a congenital anomaly/birth defect is detected in my fetus, I would Find out whether it can be managed medically or surgically.	466 (93.2)	24(4.8)	10(2.0)
Would you go for preconceptional counselling before planning your future pregnancy?	339 (67.8)	153(30.6)	8(1.6)

Almost 30% of the study population was also unaware of the teratogenic effects of alcohol and the harmful effects of smoking in pregnancy. Although the rate of smoking and alcohol abuse in India is much lower than in Western countries,<sup>15</sup> the rates have increased dramatically, especially in urban areas. Passive smoking, especially from chulhas, is still quite common in rural areas of India. The knowledge regarding advanced maternal age, maternal obesity, and consanguinity as risk factors for CAs was also deficient in more than 50% of the study population. About 61% and 39.8% were ignorant that a history of CA in one pregnancy or either of the parents, respectively, is a risk factor for its recurrence in the subsequent pregnancy. This part of India has already reported a high incidence of genetic disorders because of the very high rate of consanguineous marriages.<sup>16</sup> There is an urgent need to increase the population's awareness regarding hereditary disorders, especially because they tend to recur in subsequent pregnancies. Although most of the study population was well aware that neither coronavirus infection, nor the vaccination against it, are causative factors for birth defects, approximately 10% still believed otherwise. It is still worthy to note that 20% of the study participants were still not sure regarding coronavirus or its preventive vaccine being a risk factor for CAs as the answer they marked was "Don't know."

This study also found that ancient beliefs like supernatural factors, eating some forbidden food, and solar and lunar eclipse causing congenital malformations are still quite prevalent in this region. Even education could not deter these strong beliefs, and the participants still believed that these religious beliefs would have some solid ground. There is the need, therefore, to profile some of the existing public beliefs and opinions about a CA to integrate them into an awareness campaign program for women of reproductive age group before they plan pregnancy and also for pregnant women, especially during the antenatal visit. This study found that the mother's education status had a significant effect on the knowledge regarding CAs. This finding is similar to the studies conducted in Sri Lanka, Egypt, Nigeria, and North Iran.<sup>1,3,8,10</sup> This can be easily explained because

educated women are more likely to read, listen to, or discuss the prevention and control of disease or infirmity causing factors than their non-educated counterparts. Education increases curiosity. Therefore, educated women are more likely to search for causes, effects, and preventive measures even if a remote relative, friend, or neighbor has a congenitally anomalous baby.

More than 20% did not know that birth defects are preventable and treatable. Three-hundred thirty-nine of five-hundred participants strongly believed that birth defects invariably lead to long-term disabilities like mental retardation. This belief also leads them to opt for pregnancy termination as soon as any CA is detected in antenatal ultrasound. Educational programs with target groups including young married women are required so that women are well aware that not all birth defects are uniformly fatal. Certain mild forms like club foot, cleft lip, and palate are amenable to postnatal surgery with good outcomes.

The mean attitude score was  $4.42 \pm 0.985$  (range: 1–7), indicating overall positive attitudes. However, 84% of the study participants believed that they were not at risk of having a baby with a CA. Although most of them said they would try to find doctors specializing in fetal therapies, they were unaware of fetal medicine centers and doctors specializing in fetal medicine. Although fetal medicine is an upcoming branch of obstetrics and gynecology, specific educational programs regarding the scope of the subject, predominantly through the mass media, newspapers or radio channels, are required.

## Utility of Study

Through this study, the authors have attempted to assess the knowledge and attitude of women of the reproductive age group regarding birth defects. This is the first study addressing this population subset, but it also had certain limitations. First, the cause-and-effect relationship of the variables with the young married women's level of knowledge could not be determined because of the cross-sectional nature of the study design. Second, the power of generalizability of this



study is relatively low since we included only the women who attended the outpatient department of the AIIMS. Further studies with larger sample sizes, done at the community level, are required to assess the actual knowledge regarding birth defects.

## Conclusion

The knowledge regarding birth defects, risk factors, and preventive strategies was moderate in the majority of the study participants. Education has some bearing on the knowledge and attitude, but the knowledge base still seems to be influenced by religious beliefs. Awareness campaigns to increase the knowledge about preventable causes of birth defects and their management strategies are urgently needed in this region.

### Consent for Participation

Informed consent was obtained from all individual participants included in the study.

### Ethical Approval

Ethical clearance was obtained from the Institute Ethics Committee for Post Graduate Research (Ref. letter no.: AIIMS/BBN/IEC/SEP/2021/59-A). All procedures performed in studies involving human participants were in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study protocol was approved by the Institute Ethics Committee, All India Institute of Medical Sciences, Bibinagar, Hyderabad.

### Informed Consent

All participants gave written informed consent before the study began.

### Conflict of Interest

None declared.

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