

# A Study to Assess the Stigma and Discrimination Among Mothers of Children with Congenital Anomalies

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## ABSTRACT

### INTRODUCTION:

Congenital anomalies affect approximately 3% of newborns worldwide, contributing to 303,000 neonatal deaths annually. In India, congenital anomalies account for 8–15% of perinatal deaths and 13–16% of neonatal deaths, causing significant physical and psychological strain on caregivers. This descriptive study examines the stigma and discrimination experienced by mothers of children with congenital anomalies.

**Objectives:** To assess social stigma and discrimination among mothers of children with congenital anomalies, to correlate stigma and discrimination, and to associate these with selected demographic variables.

**Materials and Methods:** This quantitative, descriptive, cross-sectional study was conducted at the Institute of Child Health, Chennai, involving 40 mothers of children (1–14 years) with congenital anomalies. Participants were selected using a convenient sampling method. Inclusion criteria required mothers to provide direct care, with no additional children with disabilities or severe illnesses. Data were collected using demographic variables, the Perceived Stigma Scale, and the Perceived Discrimination Scale (SPARQ). Descriptive and inferential statistics were applied for analysis.

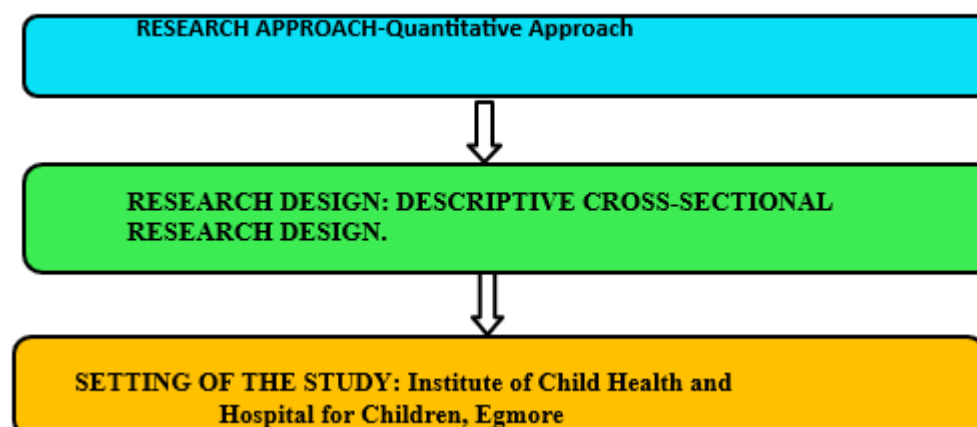
**Results:** The study revealed that 70% of mothers were aged 36–45, 35% were illiterate, and 52% were married. Most resided in rural areas, and 75% had no abortion or stillbirth history. Congenital anomalies were strongly correlated with stigma and discrimination, influenced by maternal factors like age, consanguinity, and anemia, and fetal factors such as stillbirth and low birth weight.

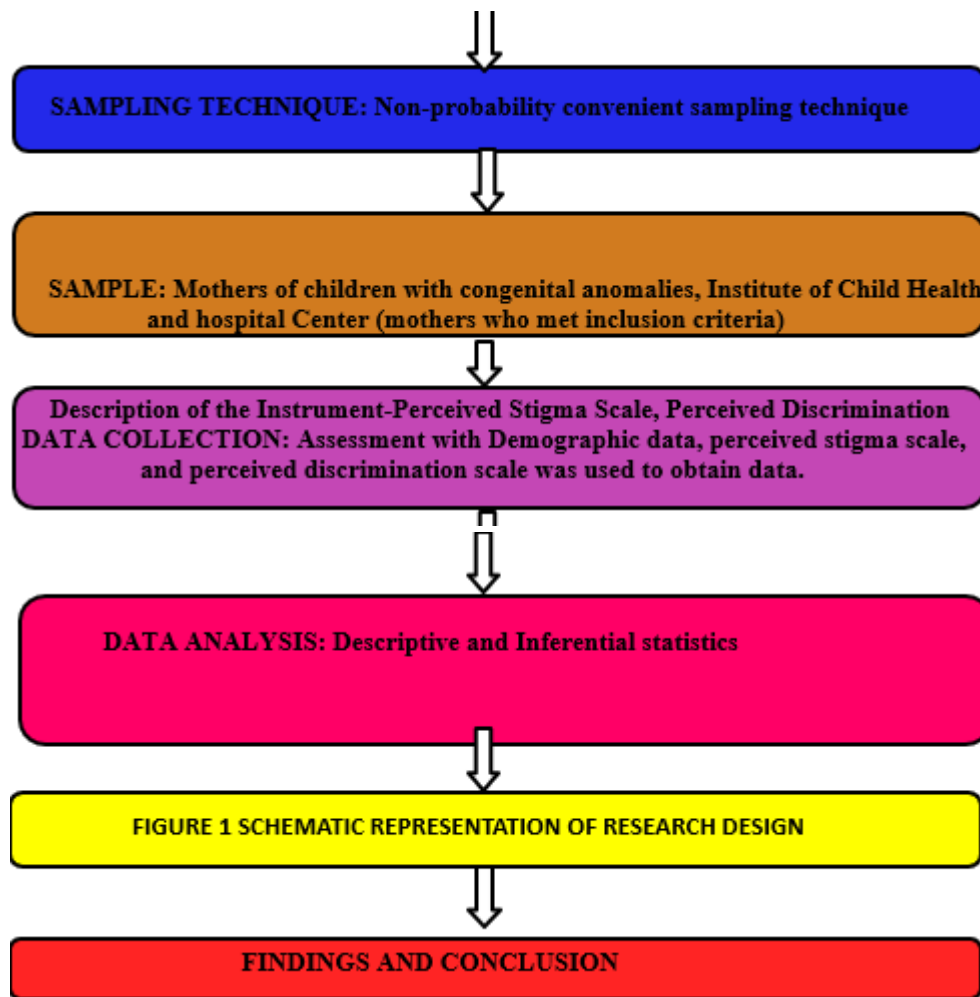
**Discussion:** The study highlighted a positive correlation between stigma and discrimination among mothers of children with congenital anomalies. Addressing associated maternal and fetal factors is crucial in reducing this burden.

**Keywords:** Stigma, Discrimination, Congenital Anomalies, Mothers, Social Attitudes.

## INTRODUCTION

The incidence and types of congenital anomalies differ in India due to ethnicity, socio-economic and environmental factors, as well as maternal age. Epidemiological data from hospital-based studies are limited. Scant data and sample preparation are at these centers, such as the Rashtriya Bal Swasthya Karyakram (RBSK), where systematic data collection on congenital anomalies is recorded, etc. Specific regional frameworks, like the Newborn and Birth Defects Database, provide standardized and comprehensive ways to track and manage these conditions. Mothers of children with congenital anomalies experience stigma rooted in social discourse on difference and inferiority to a degree that adversely affects positive coping strategies. Traditionally, congenital anomalies had been perceived as taboos involving religious beliefs like divine retribution and black magic, and this led to widespread social stigmatization. Myths persist today that continue the stigma and foster misconceptions about the causes of these anomalies. Stigma takes the form of public discrimination, negative judgment, and rejection, resulting in social isolation and emotional distress in clients' families.. Research shows that 30-40% of caregivers of a child with congenital anomalies may meet the criteria for depression or anxiety. Many caregivers struggle with financial pressure, social withdrawal, and hopelessness. These challenges are compounded by societal pressure to conform to cultural norms and values, as well as the stigmatization of congenital anomalies as an inferior human condition. Access to an appropriate level of health care for families with congenital anomalies is hampered by stigma and discrimination. Societal attitudes and lack of support from healthcare providers deprive mothers of the ability to seek timely medical interventions. Awareness programs and counseling support can address the issues, while a responsive healthcare system that ensures care for all can improve the situation.





**FIGURE 1 SCHEMATIC REPRESENTATION OF RESEARCH DESIGN**

### **FINDINGS AND CONCLUSION**

The study lasted four weeks and included mothers of children with congenital anomalies. The target population comprised mothers attending the Department of Genetics at the Institute of Child Health. Accessible participants were mothers who met the inclusion criteria, were present in the outpatient department during the study period, and were willing to participate. A total of 40 mothers were selected using convenience sampling.

Inclusion criteria required mothers of children aged 1 to 14 years diagnosed with congenital anomalies, free from chronic physical disease or neurological disorders, and without other disabled children. Participants had to provide direct care to the child, be willing to participate and understand Tamil or English. Mothers who were uninterested, other caregivers, or those whose children were critically ill during data collection were excluded.

Data collection tools included three sections: demographic variables, a perceived stigma scale, and the Perceived Discrimination Scale (SPARQ). Demographic variables were categorized into socio-demographic and obstetric variables, covering aspects like age, residence, education, gravidity, parity, prior abortions, and congenital disabilities. The Perceived Stigmatization Questionnaire (PSQ) included 21 items on a 5-point Likert scale, measuring the absence of friendly behaviors, confusing or staring behaviors, and hostility. Higher scores indicated greater perceived stigmatization. The Perceived

Discrimination Scale measured experiences of lifetime and daily discrimination, with higher scores reflecting more frequent or severe discrimination.

The study followed ethical guidelines, receiving approval from the Institutional Ethical Committee and permission from the Department Heads. Participants provided informed consent and structured questionnaires were administered, taking 10-15 minutes per participant.

Data analysis employed descriptive and inferential statistics. Frequency and percentage distributions analyzed demographic data, while mean, median, mode, and standard deviation assessed stigma and discrimination levels. Regression models and Spearman's correlation coefficient identified associations between stigma and discrimination, with a significance level of  $p < 0.05$ .

This methodology ensured a systematic approach to understanding stigma and discrimination among mothers of children with congenital anomalies, contributing valuable insights for future research and interventions.

**DISCUSSION:**

**Table 1: Frequency and percentage distribution of demographic variables of mothers of children with congenital anomalies.**

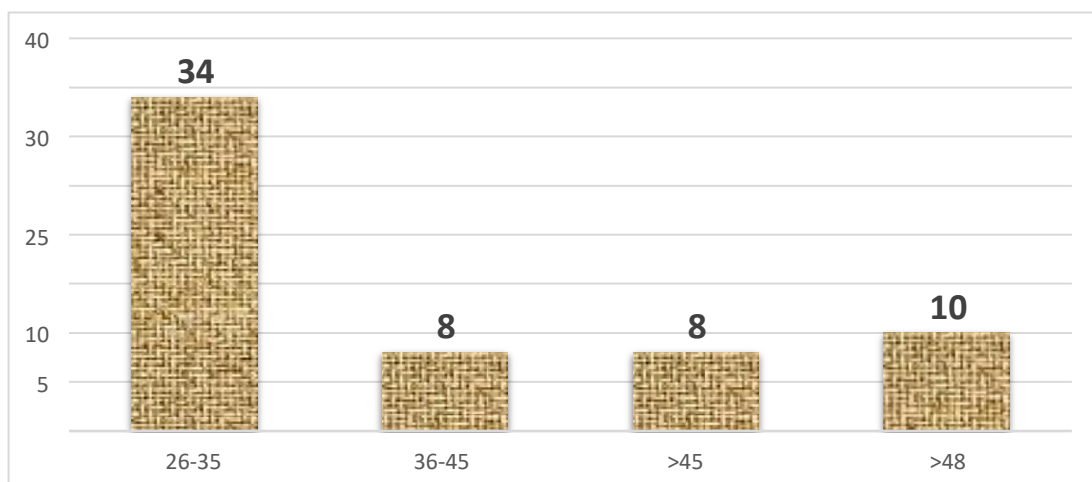
N = 40

<b>Demographic Variables</b>	<b>F</b>	<b>%</b>
<b>Age (years)</b>		
26–35 years old	10	25
36–45 years old	28	70
45 + years old	2	5
<b>Education</b>		
Illiterate	14	35
Read and write	12	30
Secondary / diploma	8	20
Bachelor	6	15
<b>Job</b>		
Housewife	14	35
Employee	12	30
Technical work	8	20
Don't work	6	15
<b>Marital status</b>		
Single parent	16	40
Married	20	50
Divorced	2	5
Widowed	2	5
<b>Consanguinity</b>		
Yes	21	52.5
No	19	47.5
<b>Length of congenital anomalies</b>		
1 year – 5 years	20	50

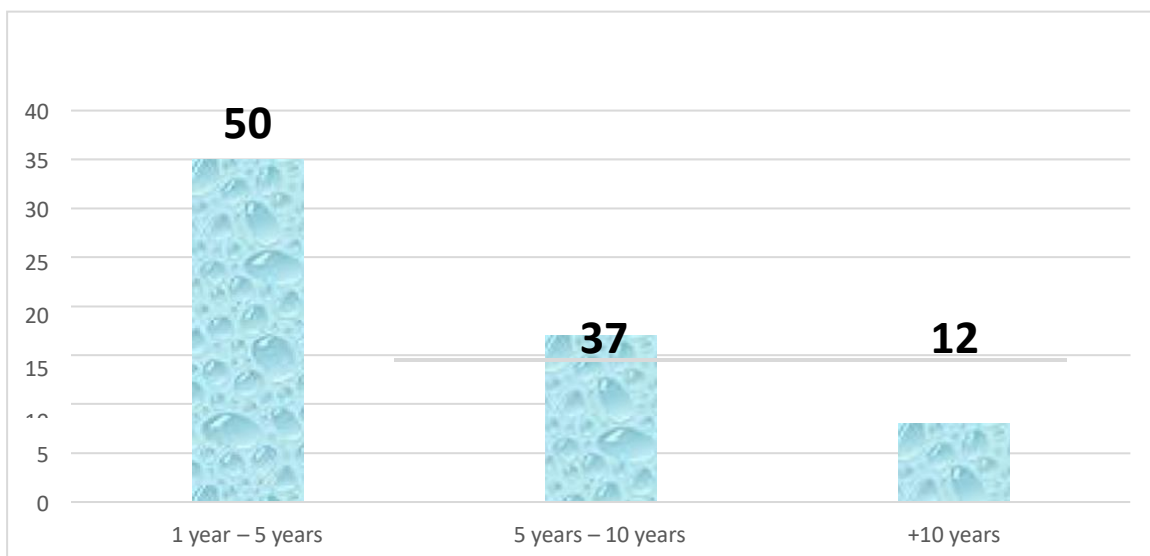
5 years – 10 years	15	37.5
+10 years	5	12.5
<b>Patient Residing</b>		
Urban	15	37.5
Rural	25	62.5
<b>Partner/husband education</b>		
No formal education	14	35
Primary school	12	30
Secondary school	8	20
College and above	6	15
<b>Partner/husband occupation</b>		
Government	14	35
Private	18	45
Self-employed	8	20
<b>Average monthly income</b>		
≤10,000	8	20
10,001–30,000	14	35
30,001–40,999	14	35
≥50,000	4	10
<b>Part II</b>		
<b>Obstetrical Data</b>		
<b>Gravidity</b>		
1	20	50
2–4	18	45
≥5	2	5
<b>Parity</b>		
1	22	55
2–4	18	45
≥5	1	2.5
<b>Number of children</b>		
1	28	70
2	11	27.5
≥3	1	2.5
<b>Stillbirth</b>		
Yes	18	45
No	22	55
<b>Took folic acid to prevent the next occurrence</b>		
Yes	35	87.5
No	5	12.5
<b>Abortion</b>		
Yes	10	25
No	30	75

Table 1 shows the demographic information of mothers of children who participated in the study. The above table shows 28(70%) belong to the age group of 36-45 years, 14(35%) of the study participants are illiterate, 21(35.0%) of the study participants are housewife, 20 (50%) of the study participants are Married in which 21 (52.5%) were married consanguinously, 20 (50%) of the study participants have the Length of congenital anomalies for 1 - 5 years, 25 (62.5%) of the study participants residing at Rural place. Regarding Partner/husband education, 14 (35%) have No formal education. 14 (35%) earn about 10,001–30,000 per month.

Obstetrical data shows that, concerning gravidity, 20 (50%) of the mothers and 22 (55%) have parity. 28 (70%) of the mothers have 1 Number of children. 35 (87.5%) of the mothers Took folic acid to prevent the next occurrence, and 30 (75%) & 22 (55%) of the mothers had no history of abortion and stillbirth.



**Figure 2: Distribution of Age in Year**



**Figure 3: Distribution of congenital anomalies in Years**

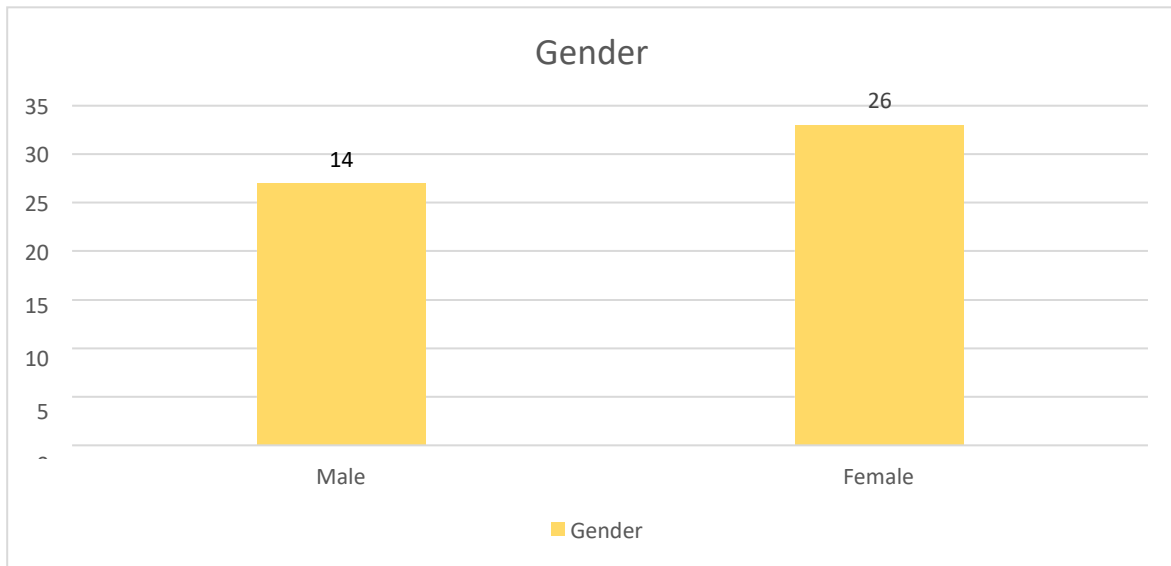


Figure 4: Distribution of gender

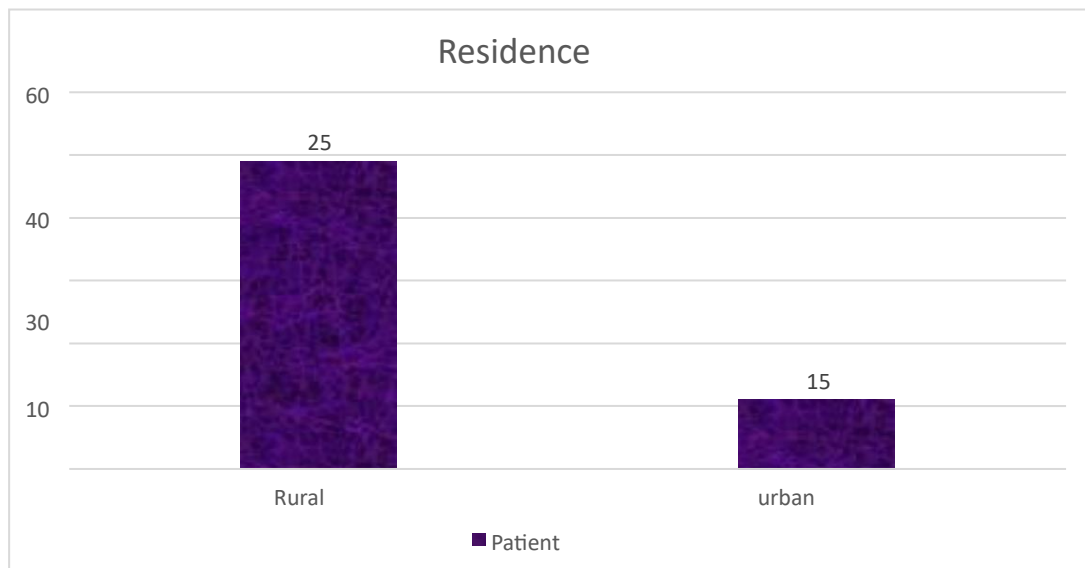


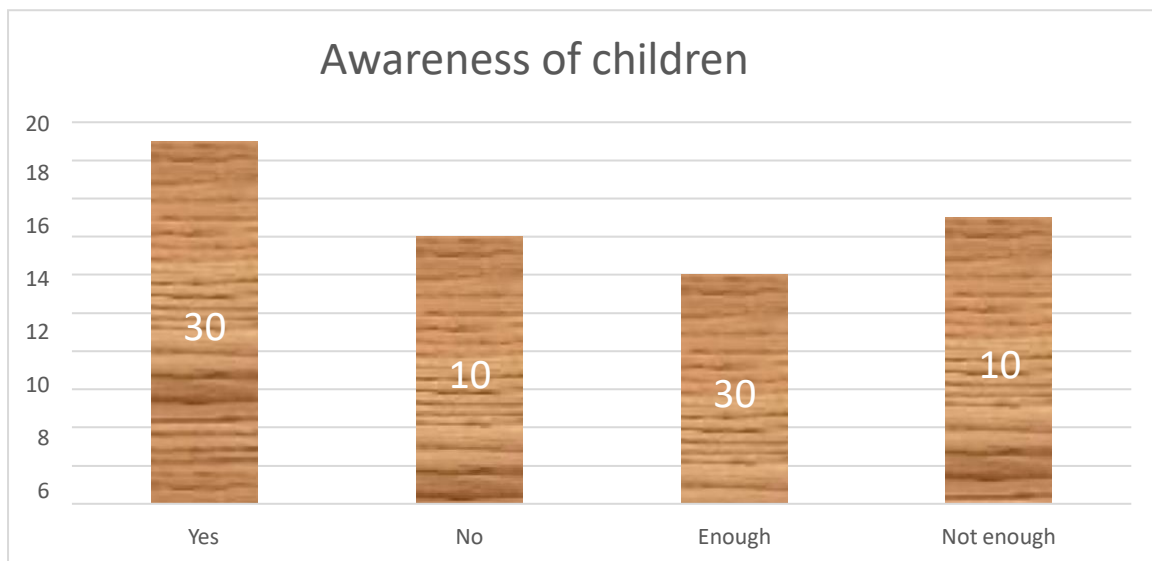
Figure 5 : Distribution of Residence

Table 2: Frequency and percentage distribution of demographic variables of Children with congenital anomalies.

Demographic variables		F	%
Age (years)	2-7	26	65
	8-14	14	35
Sex	Male	26	65
	Female	14	35
Birth order of the child	1 <sup>st</sup>	20	50
	2 <sup>nd</sup>	15	37.5
	3 <sup>rd</sup>	5	12.5
	4 <sup>th</sup> or more	-	-

Level of education	School of special needs	20	50
	Normal school	15	37.5
	Not attached to school	5	12.5
Receiving services	Yes	20	50
	No	20	50
Duration of Illness	1-7	24	60
	8 – 14	16	40
Co-Caretakers	Yes	24	60
	No	16	40
Awareness of children's illness	Yes	30	75
	No	10	25

Table 2 above shows the demographic information of children with congenital anomalies who participated in the study. The above table shows that 26(65%) belong to the age group of 2-7 years, 26(65%) of the study participants are Male, and 20(50%) of the study participants belong to first birth order. Regarding the level of education, 20(50%) of the study participants studied in a special school, 24(60%) of the study participants have a Duration of care (Years) of 1 - 7 years, 24(60%) of the study participants have Co-Caretakers, 30(75%) of the study participants are having an awareness of patient illness.



**Figure 6: Distribution of Awareness of children's illness**

**Table 3: Mean and standard deviation of Stigma and discrimination among mothers of children with congenital anomalies.**

Index	Mean (SD)	Max	Min
Stigma	33.05 (5.24)	43	19
discrimination	94.61 (11.5)	122	65



Table 3 shows that the mean and standard deviation of Stigma and discrimination among mothers of children with congenital anomalies were 33.05 (5.24) and 94.61 (11.51), respectively.

**Table 4. Association between stigma and discrimination with selected demographic variables among mothers of children with congenital anomalies**

Variable	Stigma B Coefficient	P	Discrimination B Coefficient	P
Age	0.073	0.69	0.25	0.15
Gender	-0.025	0.86	-0.006	0.96
Education	0.061	0.68	0.18	0.20
Job	-0.268	0.06	-0.16	0.23
Marital status	0.156	0.31	0.17	0.23
Relationship to Patient	-0.067	0.71	-0.12	0.48
Duration of care	0.183	0.15	0.06	0.59
Awareness of patient illness	0.804	0.34	0.86	0.31
Co-Caretakers	-0.873	0.29	-0.92	0.27

Table 4 shows no significant correlation between stigma and discrimination and these variables using Regression analysis (Table 3). There was a strong positive correlation between the stigma and discrimination variables using Spearman’s correlation coefficient ( $r_s = 0.73$ ,  $n = 85$ ,  $P < 0.001$ ).

Specific Character	$\chi^2$ Value	P Value	Odds Ratio (95% CI)
Maternal Age	6.408	$p=0.04$	0.431(0.22 to 0.83)
Paternal Age	2.601	$p=0.10$	1.51 (0.92 to 2.50)
Consanguinity	16.551	$p<0.0001$	3.116 1.77 to 5.47
Previous child with malformation	409.14	$p<0.0001$	134.10 (58.36 to 308.12)
H/o Previous abortion	12.384	$p<0.001$	2.292 (1.44 to 3.65)

**Table 5: Association of maternal factors with congenital anomalies**

Out of 40 mothers, 35 (66.6%) were in the age group of 21-35 years. Out of 40 fathers, 10 (15.9%) fathers were above the age of forty. Out of 40 mothers, 27 (6.2%) had consanguineous marriage. Out of a total of 40 mothers, 12 (14.5%) mothers had a history of previous abortion. A statistically significant association was found between congenital malformation and maternal factors like maternal age, consanguinity, previous child with malformation, history of previous abortion, and severe anemia. No statistically significant association was found between congenital malformation and paternal age. (Table: 5)

**Table 6 Multivariate analysis of maternal and infant factors associated with congenital anomalies**

Variable	Category	COR (95% CI)	P value	AOR(95%CI)	P value
Sex of the infant	Male	1.67 (0.65–4.2)	0.28	—	—
	Female				
Birth order	≥3	0.2 (0.09–0.5)	0.001	<b>8.4 (3.4–20.7%)</b>	<b>0.001</b>
	<3				
Birth weight	≥2.5	4.6(1.98–10.78)	0.001	<b>0.3 (0.1–0.9)</b>	<b>0.037</b>
	<2.5				
Gestational age at the time of delivery	Preterm	0.66(0.68–6.4) 0.7 (0.7–5.3)	0.9	—	—
	Term				
	Postterm				
Pregnancy type	Twin	0.14 (0.06–0.35)	0.001	<b>6.4 (2–18.9)</b>	<b>0.001</b>
	Singleton				

Table 6 depicts a multivariate analysis of maternal and infant factors associated with congenital anomalies in this study. Maternal age above 35 years (AOR = 6.5; 95% CI = 2.4–18), birth order above 3 (AOR = 8.4; 95% CI = 3.4–20.7), birth weight less than 2.5 kg (AOR = 0.3; 95% CI = 0.1–0.9), and singleton pregnancy (AOR = 6.4; 95% CI = 2–18.9) had a significant association with the incident of congenital anomalies, while iron folate use before and/or during early pregnancy (AOR = 0.036; 95% CI = 0.008–0.15) and being from urban area (AOR = 0.3; 95% CI = 0.1–1) had a protective effect against congenital anomalies.

## DISCUSSION

The demographic data of mothers with children who participated in the study revealed that 28 (70%) were aged between 36-45 years, 14 (35%) were illiterate, and 21 (52.5%) were homemakers. Among the participants, 20 (50%) were married, and 21 (52.5%) were in consanguineous marriages. Regarding the duration of congenital anomalies, 20 (50%) cases were between 1 to 5 years. Most participants, 25 (62.5%), resided in rural areas, with 14 (35%) of their husbands having no formal education and 14 (35%) earning between ₹10,001 and ₹30,000 monthly.

Obstetric data showed that 20 (50%) mothers had experienced multiple pregnancies (gravidity), and 22 (55%) had a history of parity. Among them, 28 (70%) had one child, 35 (87.5%) had taken folic acid to prevent further anomalies, and 30 (75%) and 22 (55%) had no history of abortion or stillbirth, respectively. The first objective was to assess social stigma and discrimination among mothers of children with congenital anomalies. The mean and standard deviation scores for stigma and discrimination were 33.05

(5.24) and 94.61 (11.51), respectively. Multiple regression analysis indicated that child behavioral and emotional difficulties, including emotional problems, hyperactivity, and lower prosocial behavior, were associated with higher stigma levels. These findings align with a study by Tayebi N [19] and Ekwere EO [20], which showed that mothers of children with significant emotional problems and hyperactivity experienced greater stigma, mainly when prosocial behavior was low.

The second objective examined the correlation between social stigma and discrimination. A strong positive correlation (Spearman's correlation coefficient,  $r_s = 0.73$ ,  $n = 85$ ,  $P < 0.001$ ) was found. Similarly, Golalipour MJ [18] reported that stigma, depression, and social anxiety were positively associated with discrimination, while surgery status was negatively correlated. Parents with higher education reported lower stigma levels than those with less education ( $P < 0.05$ ).

The third objective explored associations between stigma and discrimination with selected demographic variables. Among the 40 mothers, 35 (66.6%) were aged 21-35 years, 10 (15.9%) fathers were above 40, and 27 (67.5%) were in consanguineous marriages. A statistically significant association was found between congenital anomalies and maternal factors such as age, consanguinity, prior malformations, previous abortions, and severe anemia. No significant association was found with paternal age. Multivariate analysis revealed that maternal age above 35 years (AOR = 6.5; 95% CI = 2.4–18), birth order above three (AOR = 8.4; 95% CI = 3.4–20.7), low birth weight (AOR = 0.3; 95% CI = 0.1–0.9), and singleton pregnancy (AOR = 6.4; 95% CI = 2–18.9) were significant predictors of congenital anomalies. Protective factors included folic acid use (AOR = 0.036; 95% CI = 0.008–0.15) and urban residence (AOR = 0.3; 95% CI = 0.1–1).

These findings are consistent with studies by Shjarei H [21] and others, which identified maternal age, consanguinity, and prior medical conditions as significant risk factors. Comparisons with studies from Tanzania and Ethiopia further emphasize the protective role of folic acid during pregnancy and the increased risk associated with advanced maternal age.

## CONCLUSION

It was concluded that the stigma and discrimination suffered by mothers of children with disabilities and impairment cause suffering to mothers and are absorbed by them in their social relations, revealing judgment and attitudes of withdrawal or rejection of contact with their child. Given maternal factors associated with congenital anomalies in children were maternal age, consanguinity, having a previous child with malformation, history of previous abortion, severe anemia, and fetal factors such as stillbirth, premature babies, and low birth weight. More emphasis should be placed on prevention with appropriate antenatal care and avoiding recognized teratogenic and possible teratogenic agents. Antenatal testing, genetic counseling, and improved diagnostic and therapeutic facilities must be provided to improve the outcome.

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