

# **A Comparative Analysis of Children Born with Cleft Lips and Palates in India**

*Report prepared for*  
**Smile Train India**

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*By*

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## Preface

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Given the vast diversity in the country, inequalities in accessing and receiving quality health care exist making the occurrence of cleft lips and/or palates a serious health concern. In recent years, interventions by Non-Governmental Organisations (NGOs) as well as the government through corrective surgery programmes are contributing towards addressing this issue. Smile Train is one such non-governmental organisation (NGO) that has been sponsoring corrective surgeries for children born with cleft lips and/or palates in India. With this in mind, a study was instituted, by Smile Train in collaboration with Tata Institute of Social Sciences (TISS), Mumbai in 2000 to derive the number of children experiencing and to bring out various perceptions people have about the incidence of such deformities in the community. Subsequently, appropriate and effective interventions in the curative and preventive aspects related to these deformities were looked into. Since 2000, Smile Train has sponsored over 4,25,000 surgeries across India<sup>1</sup>.

During the last 14 years, the organisation felt that it is time to assess the impact the survey had on select locations in India. Accordingly, four geographically and socio-economically diverse districts were chosen for the study – Nashik (Maharashtra), Jaipur (Rajasthan) and Madurai (Tamil Nadu) and Amritsar (Punjab). Several persons have contributed in various capacities for the successful execution of this major project. My sincere thanks and deepest gratitude to all of them:

- Sincere thanks to Dr. Satish Kalra, Regional Director (South Asia), Smile Train for his valuable suggestions on the draft report
- We are grateful to Prof. S. Parasuraman, Director, TISS for his guidance and encouragement throughout the project
- We would also like to thank Dr. Leela Imam, Smile Train, Bangalore for her coordination and assistance during the project
- The assistance of the field investigators in completing data collection on time is also appreciated. We thank Mr. Mandar Shelar, Mr. Mayur Kadam and Mr. Shailesh Juwatkar (Maharashtra team); Mr. Praveen Kumar and Mr. Vikash Sharma (Jaipur team); Ms. Sukhpreet Kaur and Vishal Sharma (Amritsar team) and Mr. N. Selva Kumar and Mr. N. Kannan (Madurai team). Special thanks to Ms. Jyoti Thakur for

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<sup>1</sup> Source: [www.smiletrainindia.org](http://www.smiletrainindia.org)

coordinating the field investigations in Jaipur and Amritsar and for assisting in drafting the report

- We would also like to thank the TISS project staff in Mumbai, Mr. Gandharva Pednekar, Ms. Rashmee Sharma, Ms. Priyanka Bhosale and Ms. Niharika Rao for their continual assistance throughout the duration of the project
- Our sincere gratitude to the doctors, dentists, panchayat officials, anganwadi teachers, local NHO representatives, Smile Train partner institutions and doctors, Integrated Child Development Scheme office staff, other medical practitioners and community members who helped us locate the patients/respondents and their families
- Last but not the least, We are most grateful to the very cooperative respondents for providing us with the requisite information and without which this study would never have been possible

**Prof. S. Siva Raju and Dr. P.M. Sandhya Rani**

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TISS Mumbai

# Chapter 1

## Introduction

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Every three minutes, a child is born with a cleft. Cleft lips and cleft palates can have a significant impact both on the life and livelihood of the child.<sup>2</sup> In 2008, the World Health Organisation (WHO) has recognised that non-communicable diseases, including birth defects cause significant infant mortality and childhood morbidity and have included cleft lip and palate in their Global Burden of Disease (GBD) initiative. This is expected to garner interest in India in the registration of birth defects and international efforts aimed at improving quality of care and ultimately prevention of non-syndromic clefts of the lip and palate.<sup>3</sup>

While clefts of the lip and/or palate (CLP) are immediately recognisable distortions of normal facial structure and as such do not pose a severe morbidity risk, CLP does cause considerable morbidity to affected children and imposes a substantial financial risk for the families.<sup>4</sup> Individuals with CLP may experience problems with feeding, speaking, hearing and social integration that can be corrected to varying degrees by surgery, dental treatment, speech therapy and psychosocial intervention. With reference to access and reception of good quality health care system for the timely correction of cleft lips and palates the scenario differs in developing and developed countries. In developing countries, untreated cleft lips and palates are found with increasing frequency and patients often present to the surgeon far past the optimal time for closure of the cleft deformities.<sup>5</sup> However, in developed countries, such disabilities are corrected well before the patients turn 20 years of age. For instance, in the United States, children receiving cleft lip and palate surgeries are likely to receive multiple surgeries by the time they are 16.6 years.

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<sup>2</sup> Source: Cleft Lip and Palate FAQ, Operation Smile; <http://www.operationsmile.org>

<sup>3</sup> Source: Addressing the challenges of cleft lip and palate research in India; Peter Mossey and Julian Little; Indian Journal of Plastic Surgery Oct 2009; 42(Suppl): S9–S18  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2825065/>

<sup>4</sup> Source: ReSurge International; <http://www.resurge.org>

<sup>5</sup> Wasiu L Adeyemo, Mobolanle O Ogunlewe, Ibronke Desalu et.al; Cleft deformities in adults and children aged over six years in Nigeria: Reasons for late presentation and management challenges; Dove Press journal: Clinical, Cosmetic and Investigational Dentistry; 27 November 2009

In addition, they typically receive orthodontic care and speech therapy over a number of years. It appears that very little is known about the long-term impact of a single surgery in a developing nation without a comparable support system.<sup>6</sup> Reconstructive surgery can successfully repair cleft lip and cleft palate. However, in many developing countries, where adequate medical care may not be available or affordable, it is common for people never to receive corrective surgeries. Global cleft surgery missions have provided much-needed care to millions of poor patients worldwide. Still, surgical capacity in low- and middle-income countries is generally inadequate. Through surgical missions, global cleft care has largely ascribed to a vertical model of healthcare delivery, which is disease specific, and tends to deliver services parallel to, but not necessarily within, the local healthcare system.<sup>7</sup>

In this context, a study of one such voluntary corrective surgery mission was thus instituted to understand the occurrence of cleft lips and palates among children in select locations in India. The focus was to examine the reported cases of cleft lips and palates and to understand the perceptions among community members about its occurrence and treatment. Based on the findings of the previous study, the present study looks at the attitudes and beliefs about cleft lips and palates and also aims to assess the impact of Smile Train interventions over the last 15 years. It is expected that the present assessment will assist in the evaluation of programmes and will help to improve strategies in the future. It also examines the contribution made by the patients after surgery with respect to their education, their economic and their occupational status. The main objectives of the study are:

- understanding the socio-economic, demographic and health status of the families having children with cleft lips and/or palates;
- knowing the family history in terms of occurrence of such deformities among their family members;
- focusing on the perceptions, attitudes and beliefs of these families towards the nature, causes and effects of the disabilities among children so as to compare with the earlier

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<sup>6</sup>Developing-world corrective surgery; Give Well, Charity Research  
<http://www.givewell.org/international/health/surgery#Cleftlippalate>

<sup>7</sup> Source: An Opportunity for Diagonal Development in Global Surgery: Cleft Lip and Palate Care in Resource-Limited Settings; Pratik B. Patel,1,2 Marguerite Hoyler,1,2 Rebecca Maine,1,2,3 Christopher D. Hughes,1,2,4 Lars Hagander,1,2,5 and John G. Meara1,2; Plastic Surgery International Volume 2012 (2012), Article ID 892437, 10 pages <http://dx.doi.org/10.1155/2012/892437>

attitudes, perceptions and beliefs which are reported by the communities in the base line study;

- examining attempts made earlier by these families in treating the deformity of their children and assessing the socio-economic impact of intervention programs carried out by Smile Train and various organisations in improving the quality of life of the beneficiaries and the extent to which they have succeeded in addressing the deformities and to suggest suitable and effective policies and programs for the care of the children born with cleft lips and/or palates deformities in India so as to make the society cleft free.

## Chapter 2

### Methodology

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The present study attempted to find out the extent of incidence of cleft lips and/or palate among children in four geographically and socio-economically varied districts in India and to understand their socioeconomic and health situation. It also attempts to compare data analyzed earlier and understand the changes in the lives of the respondents, their well-being and such related aspects. The present study will help evolve effective interventions in aspects related to these deformities.

The methodology adopted in the earlier conducted study have guided in finalising the methodology for the present study. While information about patients was largely unavailable then, patient records from local medical institutions, information about children with cleft lips and/or palates from anganwadi teachers, panchayat officials and community members were used to track down present patients and their family members. Moreover, a list of treated patients was also provided by Smile Train officials as well.

#### Study Areas

Four states, namely Maharashtra, Rajasthan, Punjab and Tamil Nadu were selected for the present study. These states are not only geographically representative for India, but also they vary in levels of development. Field staff utilised various sources of information like multipurpose health workers (both male and female), anganwadi teachers, panchayat officials, traditional birth attendants (*dais*), local NGO representatives and cleft cases themselves for the identification of cleft cases in the study areas. Altogether 1051 cleft cases were reported in the study districts of Nashik (349), Jaipur (352), Madurai (172) and Amritsar (178). An interview schedule covering major issues namely identification information, background information of a person with cleft lip and/ or palate, their perceptions of the disability and their efforts to correct the disability was administered to the cleft cases and necessary information from them was obtained.



**Table 2.1: Profile of Selected Districts**

<b>Characteristics</b>	<b>Nashik</b>	<b>Jaipur</b>	<b>Madurai</b>	<b>Amritsar</b>
Population (in millions)	1.5 (117)	3.1 (68)	1.2 (67.86)	2.5 (27)
Density of population(per sq.kms)	393 (365)	598 (928)	698 (555)	932 (551)
Sex ratio(no. Of females/1000 males)	934 (929)	909 (928)	990 (996)	879 (895)
Literacy rate(in percentage)				
Persons	82.31(82.34)	75.51(66.11)	83.45(80.09)	85.27(75.84)
Males	88.17(88.38)	86.05(79.19)	89.72(86.77)	88.09(80.44)
Females	76.08(69.87)	64.02(47.76)	77.16(73.14)	82.09(62.52)
Percentage of Urban population to total population	42.53(45.22)	52.40(24.87)	60.78(48.40)	53.58(37.48)
Number of villages	1938	2199	610	35

*Note: Figures in parentheses refer to states*

**Sources:**

- a) [http://censusindia.gov.in/2011census/censusinfodashboard/stock/profiles/en/IND003\\_Punjab.pdf](http://censusindia.gov.in/2011census/censusinfodashboard/stock/profiles/en/IND003_Punjab.pdf)
- b) <http://www.census2011.co.in/census/district/602-amritsar.html>
- c) <http://www.census2011.co.in/census/district/45-madurai.html>
- d) <http://www.census2011.co.in/census/state/tamil+nadu.html>
- e) <http://www.census2011.co.in/census/state/rajasthan.html>
- f) <http://www.census2011.co.in/census/district/435-jaipur.html>
- g) <http://www.census2011.co.in/census/district/354-nashik.html>
- h) <http://www.census2011.co.in/census/state/maharashtra.html>
- i) <http://nashik.nic.in/htmldocs/zillaparishad.htm>
- j) <http://www.punjabdata.com/Villages-In-Amritsar.aspx>

**Data Collection**

The field investigators undertook regular visits to the study areas to meet the respondents and collect information about the study from them. An interview schedule was developed exclusively for the study bearing in mind the objectives of the study (see Appendix). Field investigators were selected from study states itself due to familiarity with the local language. Aside from interview schedules, the investigators have also recorded their field observations and these have been presented separately.

**Data Analysis**

The collected data was analysed by using software called Statistical Package for Social Sciences (SPSS). Besides understanding the impact of Smile Train interventions, the incidence

rate of cleft lips and palates in the study districts and for the country as a whole was also calculated.

### **Chapterisation**

The findings of the study have been presented in ten chapters; the first chapter describes the scenario of cleft lips and/or palates the world over and in India and the interventions made in this regard. The methodology adopted in the study is covered in the second chapter. The major findings, feedback pertaining to the study and incidence rates in the study areas have been presented in chapters three to eight. The next chapter consists of field experiences from the study areas. The report concludes with the final chapter on the summary and recommendations for the study.

## Chapter 3

### Profile of Persons with Cleft Lips and/or Palates

A profile of the persons with cleft lips and/or palates is expected to help directing timely and effective interventions. In this regard, data on the sex, age, marital status, education and occupation was collected and is presented here.

#### SEX

Sex-wise analysis of the persons with cleft lips and/or palates reveals that two thirds (63.1%) are males and about one third (36.4%) are females as seen in all the study areas (Jaipur, Madurai and Amritsar) with the exception of Nashik, where more than half (59.3%) males and 40.7 per cent females had cleft lips and or/palates.

**Table 3.1: Profile of persons with cleft lip and/or palate**

S.No.	Profile					
1	<b>Sex:</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
	Male	65.9	59.3	64.6	66.9	63.1
	Female	34.1	40.7	35.5	33.2	36.4
2	<b>Age (in years):</b>					
	Less than 5	45.7	38.7	30.2	23.6	37.1
	5.1- 10	22.4	19.5	12.2	13.5	18.3
	10.1-15	11.1	18.3	10.5	15.2	14.1
	15.1-20	7.1	8.3	9.9	12.9	8.9
	More than 20	13.6	15.2	37.2	34.8	21.6
	Mean	10.1	10.5	16.5	17.9	12.6
3	<b>Marital status:</b>					
	Single	91.8	89.4	42.6	38.2	74.0
	Married	8.0	7.4	19.5	19.7	11.6
	Other	0.2	3.1	36.6	42.1	14.2
4	<b>Level of education:</b>					
	Illiterate	24.4	1.4	9.9	18.0	13.3
	Not attending school yet	19.9	28.1	23.8	23.6	23.9
	Lower KG	4.3	10.9	2.3	8.4	6.9
	Primary (Class I-	21.0	20.3	14.5	12.4	18.3

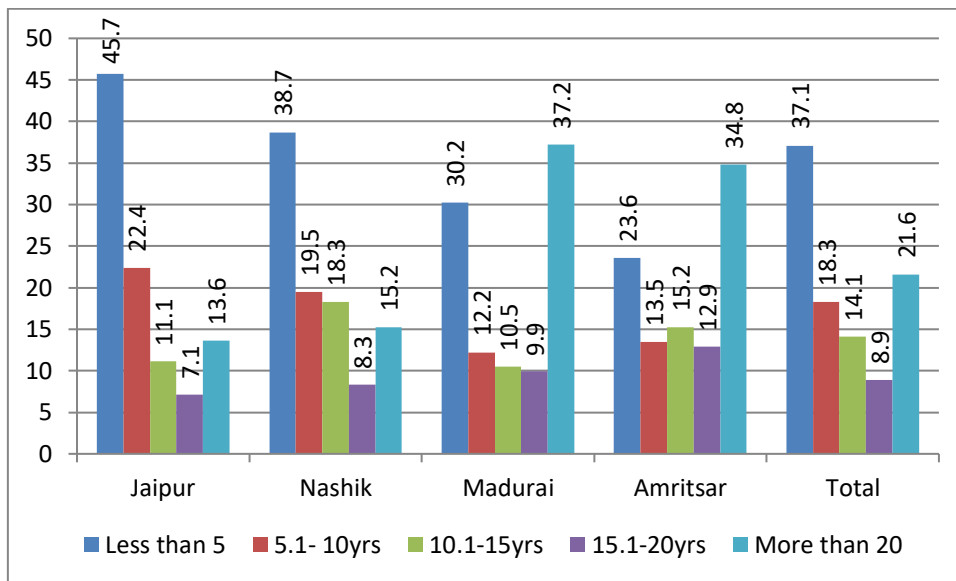
	IV)					
	Secondary (Class V-X)	16.8	25.2	27.9	26.4	23.0
	Collegiate (Class XI onwards)	7.4	11.2	15.1	9.0	10.2
	Vocational Training	0.0	0.9	0.6	0.0	0.4
	Technical	0.3	0.6	2.9	0.0	0.8
	Other	6.0	1.4	2.9	2.2	3.3
<b>5</b>	<b>Occupational status</b>					
	Student	46.0	51.6	32.6	29.2	42.8
	Not yet going to school	41.2	28.4	25.6	16.9	30.3
	Hawker/Vendor	0.0	0.0	0.0	2.8	0.5
	Daily wage earner	2.0	1.1	11.6	15.7	5.6
	Shopkeeper	1.1	1.7	0.0	1.1	1.1
	Regular worker in industry/workshop	0.9	0.6	5.2	0.0	1.3
	Regular worker in office	0.9	0.6	3.5	0.0	1.0
	Auto driver/Bus conductor/Bus driver	0.0	0.9	0.6	0.6	0.5
	Agriculturist	2.0	3.7	2.3	5.1	3.1
	Housewife	3.4	3.4	3.5	5.1	3.7
	Other	2.6	6.6	8.1	21.9	8.1
	Presently Unemployed	0.0	1.4	7.0	1.7	1.9

## AGE

As per the age distribution among the respondents, a majority (37.1%) of them were below 5 years of age, followed by less than a quarter (21.6%) of them who were more than 20 years of age. Few (18.3%) of the respondents with cleft lips and/or palates are between 6 to 10 years of age, very closely followed by 14.1 per cent of them who are between 11 to 15 years of age while 8.9 per cent of the respondents are in the age group of 16 to 20 years.

District-wise data shows little variation with similar proportions of respondents in Jaipur (45.7%), Nashik (38.7%), Madurai (30.2%) and Amritsar (23.6%) below 5 years of age. Variations were seen among the respondents with cleft lips and/or palates above 20 years of age in the study areas of Madurai (37.2%) and Amritsar (34.8%) and those from Nashik (15.2%) and Jaipur (13.6%).

Nearly a quarter (22.4%) of the respondents in Jaipur, followed by 19.5 per cent, 13.5 per cent and 12.2 per cent respondents in Nashik, Amritsar and Madurai respectively who are in the age group of 6 to 10 years. Among the respondents in the age group of 11 to 15 years, 18.3 per cent of them are in Nashik, followed by 15.2 per cent of them in Amritsar, while 11.1 per cent respondents in Jaipur and 10.5 per cent in Madurai are in the same age group. The mean age of all the respondents is 12.6 years. District-wise, the mean age of persons with cleft lip and/or palate is 17.9 years in Amritsar, 16.5 years in Madurai, 10.5 years in Nashik and 10.1 years in Jaipur.



## MARITAL STATUS

Across all districts, data on marital status shows that nearly three-fourth (74.0%) of the respondents are single with few of them being married and widowed or divorced. District-wise data reveals that a majority (91.8%) of the respondents in Jaipur are single, followed by 89.4 per cent of them from Nashik, who are also married. Less than half (42.6%) of the respondents from Madurai are married while those in Amritsar (38.2%) are married. Around 42.1 per cent of them respondents from Amritsar report their marital status in the 'other' category (either widowed or divorced) while 36.6 per cent of them from Madurai report the same marital status. An almost equal proportion of respondents in Amritsar (19.7%) and Madurai (19.5%) are married. Few (8.0% and 7.4%) of the respondents from Jaipur and Nashik respectively are married.

Given the high proportion of single respondents, a respondent observes:

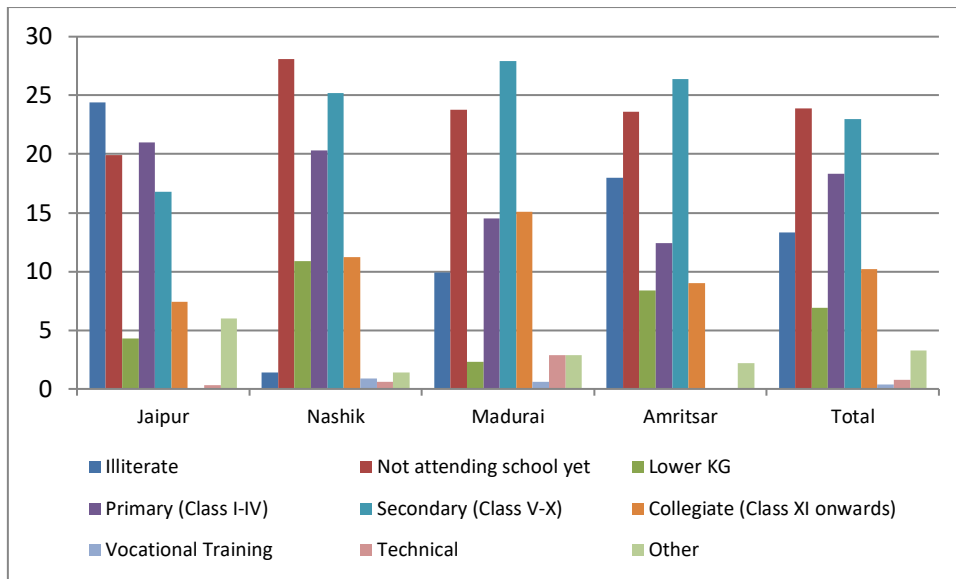
*“Today even normal girls find it difficult to get suitable groom, so the chances of girls with deformities like ours to get married are extremely bleak. For us, Smile Train is no less than God”*

## **LEVEL OF EDUCATION**

Overall, a majority of the patients with cleft lip and/or palates are illiterate (23.9%), while an almost equal proportion (23.0%) of the respondents is in the secondary level of their education (that is, Class V-X). About 18.3 per cent of the total respondents are studying in the primary level (Class I-IV) and 13.3 per cent of them are illiterate. One-tenth (10.2%) of the respondents are in college (Class XI onwards).

District-wise data shows that illiterate respondents are found in a higher proportion in Jaipur, with almost a quarter (24.4%) of them reporting the same. Few (18.0%) respondents in Amritsar are illiterate, while 9.9 per cent of them, followed by 1.4 per cent of them in Madurai and Nashik respectively, who are illiterate. Similar proportions of respondents across all districts are seen as not yet attending school viz., 28.1 per cent respondents from Nashik, 23.8 per cent and 23.6 per cent in Madurai and Amritsar and 19.9 per cent respondents in Jaipur. A little over a quarter (27.9%) of the respondents is in the secondary, followed very closely by 26.4 per cent and 25.2 per cent respondents who report the same educational level. About 16.8 per cent respondents from Jaipur are studying between classes V and X.

About 21.0 per cent respondents from Jaipur are in the primary, followed very closely by 20.3 per cent of them from Nashik who are studying in the same section. Few (14.5% and 12.4%) of the respondents from Madurai and Amritsar respectively are in the primary. With regard to those respondents who are in college, a majority (15.1%) of them are from Madurai, followed by 11.2 per cent of the respondents in Nashik who are college students while 9.0 per cent and 7.4 per cent of respondents from Amritsar and Jaipur respectively who are college going students. One-tenth (10.9%) of the respondents from Nashik are in the lower kindergarten (KG) level. About 8.4 per cent of them from Amritsar are in lower KG, followed by 4.3 per cent of the respondents and 2.3 per cent from Jaipur and Madurai respectively who are also in lower KG.



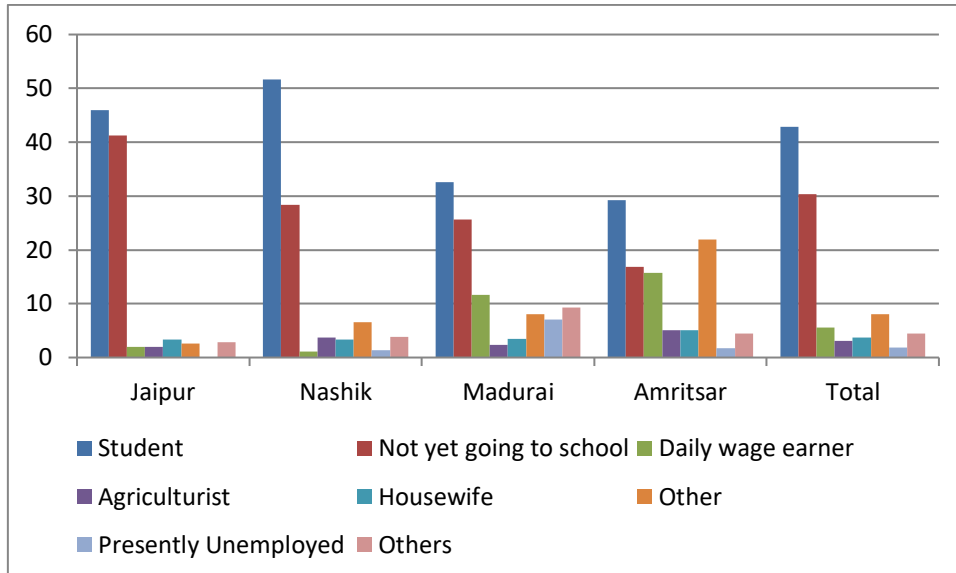
## OCCUPATIONAL STATUS

Data on the occupational status of the persons with cleft lip and/or palates reveals that 42.8 per cent of them are students, followed by 30.3 per cent of them who are not yet going to school. Few (5.6%) of them are daily wage earners. About 3.7 and 3.1 per cent of the respondents are housewives and agriculturists respectively. Very few (1.9%) of the respondents are presently unemployed.

District-wise data shows some variations with regard to the occupational status of the respondents. Among those who are students, a little over half (51.6%) are from Nashik, followed by 46.0 per cent who are from Jaipur while 32.6 per cent students are from Madurai and 29.2 per cent are from Amritsar. Less than half (41.2%) of the respondents who are not yet going to school, live in Jaipur. More than a quarter (28.4%) of the respondents who are not yet going to school are from Nashik, followed closely by 25.6 per cent of them who are from Madurai. Few (16.9%) of the respondents from the same category are from Amritsar. More than one-tenth (15.5%) of the daily wage earners with cleft lip and/or palate are from Amritsar, followed by 11.6 per cent of them who are from Madurai, while on the other hand, 2.0 per cent and 1.1 per cent daily wage earners from Jaipur and Nashik have cleft lips and/or palates.

From among the districts, Madurai shows the highest (7.0%) proportion of presently unemployed people with cleft lips and/or palates, with the other districts showing relatively lower proportions of unemployed cleft lip and/or palate patients. About 5.1 per cent respondents in Amritsar each with cleft lip and/or palate are housewives and agriculturists,

followed by 3.7 per cent respondents in Nashik who are also agriculturists, while 3.5 per cent housewives from Madurai have cleft lips and/or palates. About 3.4 per cent respondents each in Nashik and Jaipur are housewives. Very few (2.3%) and (2.0%) respondents from Madurai and Jaipur respectively are agriculturists.



### TYPE OF CLEFT CASES

The different types of cleft cases include unilateral cleft lip, bilateral cleft lip. Cleft palates may be partial or complete. In some cases, these may be unilateral cleft lip and palate or bilateral cleft lip and palate.

A look at the data on type of cleft cases reveals that, a majority (41.4%) of the respondents across all regions have unilateral cleft lips, while 19.4 per cent of them who have unilateral cleft lips and palates followed closely by 16.9 per cent of them who have bilateral cleft lips. Few (14.7% and 13.3) cases of partial and complete cleft palates respectively are also seen and 11.2 per cent patients with bilateral cleft lip and palates are observed.



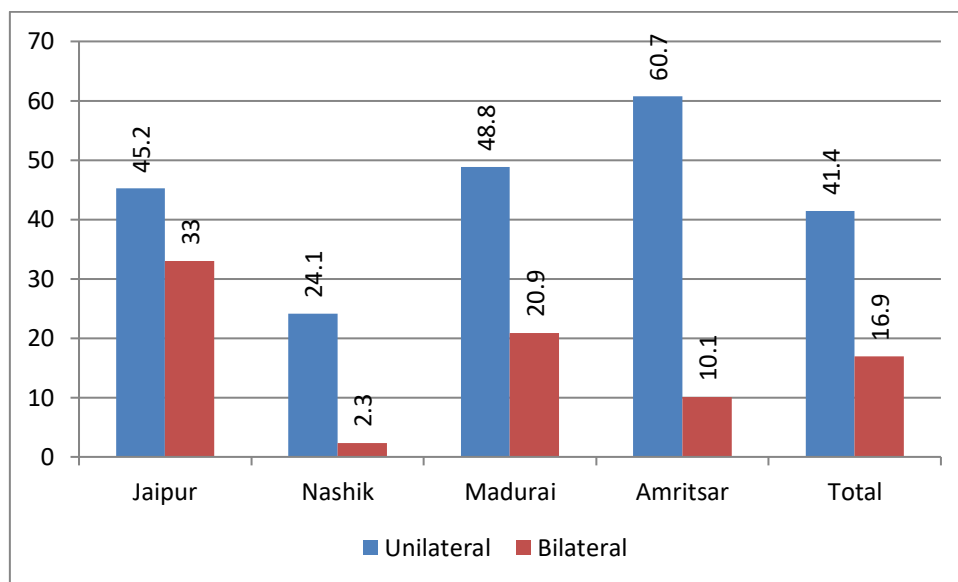
**Table 3.2: Type of Cleft Lip and /Palate**

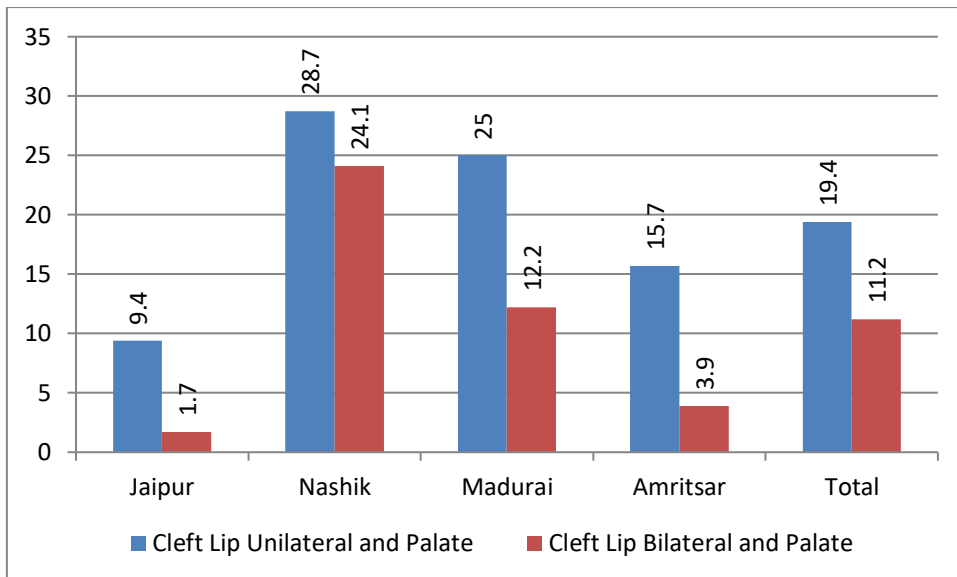
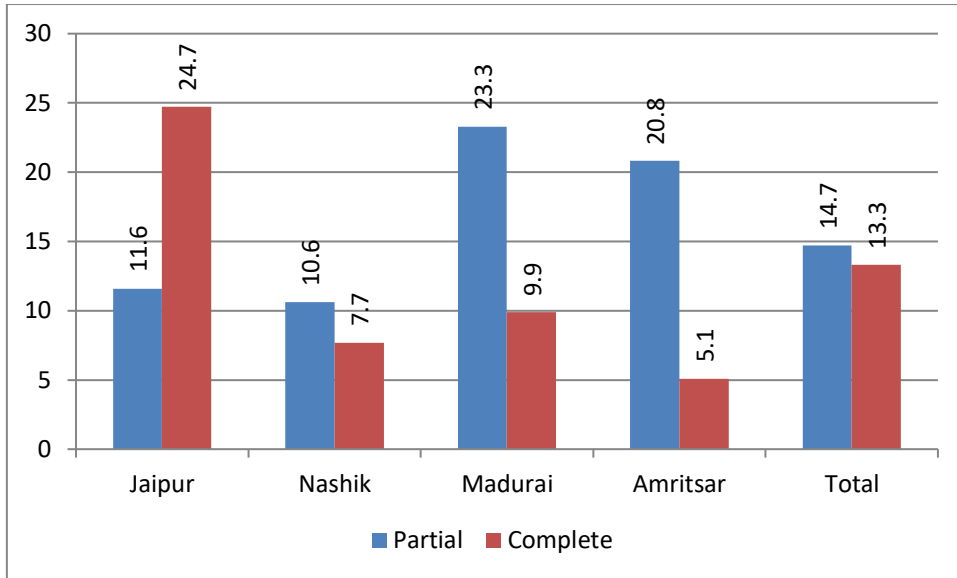
<b>Type of Cleft Lip and /Palate</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
<b>Cleft Lip</b>					
Unilateral	45.2	24.1	48.8	60.7	41.4
Bilateral	33.0	2.3	20.9	10.1	16.9
<b>Cleft Palate</b>					
Partial	11.6	10.6	23.3	20.8	14.7
Complete	24.7	7.7	9.9	5.1	13.3
<b>Both</b>					
Cleft Lip Unilateral and Palate	9.4	28.7	25.0	15.7	19.4
Cleft Lip Bilateral and Palate	1.7	24.1	12.2	3.9	11.2

District-wise data shows that Amritsar has the highest (60.7%) incidence of unilateral cleft lips while less than half (48.8%) of the respondents from Madurai have unilateral cleft lips, followed by 45.2 per cent such cases are seen in Jaipur. About 33.0 per cent of the respondents from Jaipur have bilateral cleft lips. More than a quarter (28.7%) of the respondents from Nashik report unilateral cleft lips. Data from Jaipur shows that 24.7 per cent of the respondents have complete cleft palates, very closely followed by 24.1 per cent patients each with bilateral cleft lips and palates and unilateral cleft lips from Nashik. Patients with partial cleft palates (23.3%) and bilateral cleft lips (20.9%) are seen in Madurai followed by Amritsar which shows that 20.8 per cent patients have partial cleft palates.

Around 15.7 per cent respondents from Amritsar report having unilateral cleft lips and palates, while 12.2 per cent of them from Madurai have bilateral cleft lips and palates. Slightly over one-tenth (11.6%) patients with partial cleft palates belong to Jaipur followed very closely by 10.6 per cent of the respondents with the same condition from Nashik. About 10.1 per cent of the respondents from Amritsar report having bilateral cleft lips. Few (9.9%, 7.7% and 9.4%) respondents from Madurai, Jaipur and Nashik have complete cleft palates and unilateral cleft lips and palates respectively. Very few (5.1% and 3.9%) respondents from Amritsar are seen to have complete cleft palates and bilateral cleft lips and palates respectively. About 2.3 per cent incidences of bilateral cleft lips are seen in Nashik.

When compared with the data from the study carried out in 2014, there is a decrease in the number of patients with cleft lip/palate in the above 20 age group suggesting a positive impact of intervention across districts. However, the proportion of single persons with cleft lip/palate is more in the present study while that of married people with the disability is seen to decrease from the previous study. Interestingly, the number of illiterate persons with cleft lip/palates is seen to decrease significantly from the previous study (by 18.5%). On the contrary, incidences of cleft lips/palates among collegiate students has almost doubled in the present study (from 4.9% to 10.2%). Similar trends are seen among respondents with cleft lips/palates among students (from 26.4% to 42.8%) and among those who are not yet going to school (from 16.0% to 30.3%). With respect to the type of cleft cases, respondents with bilateral cleft lips are seen more in the present study as compared to the data from the previous one (from 3.8% to 16.9%). Likewise, an increasing number of respondents with partial and complete palates are seen in the present study (3.6% to 14.7% and 0.9% to 13.3% respectively).



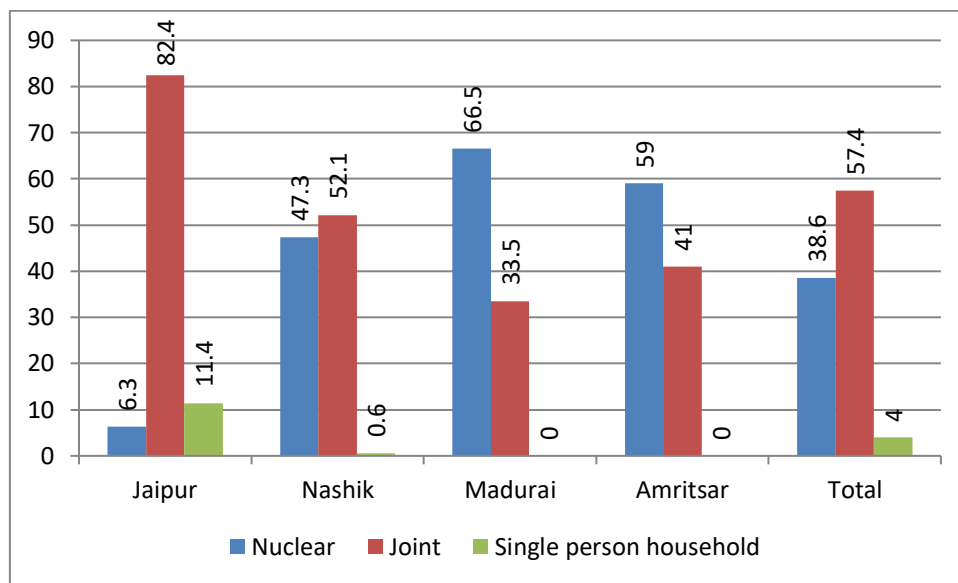


## Chapter 4

### Family Background

Family background covers aspects important to understand the factors that may have an impact on the patients with cleft lips and/or palates, health seeking behaviour and such other factors. The family background in the present study covers the type of family, family size and family income.

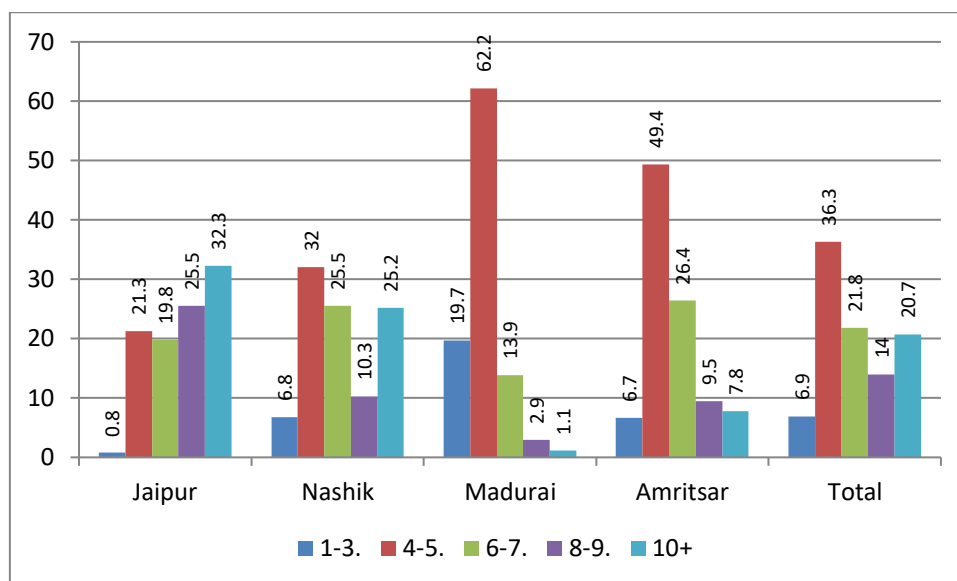
#### TYPE OF FAMILY



With regard to the type of family, more than half (57.4%) of the respondents live in joint families, followed by 38.6 per cent of them who live in nuclear families and very few (4.0%) of the respondents are in a single person household. A few variations were seen among districts with a majority (82.4%) of the respondents from Jaipur who live in joint families, followed by 66.5 per cent respondents from Madurai who live in nuclear families.

More than half (59.0%) of the respondents from Amritsar are in nuclear families while 52.1 per cent of them from Nashik live in joint families and 47.3 per cent of them from the same district live in nuclear families. About 41.0 per cent respondents from Amritsar live in joint families, followed by 33.5 per cent of them from Madurai who also live in joint families. A few (11.4%) of the respondents from Jaipur live in single person households, the highest among districts.

## FAMILY SIZE



Overall, most (36.3%) of the households have four to five members in the household. Less than a quarter (21.8%) of the respondents have six to seven family members residing in their house, followed very closely by 20.7 per cent respondents reporting more than 10 persons in their households. About 14.0 per cent respondents state eight to nine member-households and few (6.9%) respondents report households with up to three family members.

Data from the districts show that a majority (62.2%) of the respondents with 4-5 family members are in Madurai, while less than half (49.4%) of them with the same number of family members live in Amritsar. With regard to 10-plus sized households, Jaipur ranks first (32.3%) among the districts. About 32.0 per cent of respondents from Nashik with report households with 4 to 5 members while 26.4 per cent respondents from Amritsar state that they have 6-7 family members and a quarter (25.5) in Nashik report having the same number of family members and another 25.2 per cent in the same district have more than 10 persons in their households. About 21.3 per cent respondents in Jaipur say that they have 4-5 members in their household while 19.8 per cent of them in the same district have 6-7 family members in a household, closely followed by a similar proportion (19.7%) of respondents in Madurai who state that they have up to 3 family members in their household. Few (13.9% and 10.3%) of the respondents from Madurai and Nashik respectively have 6-7 and 8-9 family members in their households respectively. The mean family size is 7.1 family members for all four study areas combined together and with respect to the districts, it is 8.5 for Jaipur, 7.4 for Nashik, 6.0 for Amritsar and 4.4 family members for Madurai.

**Table 4.1: Family Background of the Person with Cleft Lip and/or Palate**

S.No.	Family Background	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
1	<b>Type of Family:</b>					
	Nuclear	6.3	47.3	66.5	59.0	38.6
	Joint	82.4	52.1	33.5	41.0	57.4
	Single person household	11.4	0.6	0.0	0.0	4.0
2	<b>Family Size:</b>					
	1-3	0.8	6.8	19.7	6.7	6.9
	4-5	21.3	32.0	62.2	49.4	36.3
	6-7	19.8	25.5	13.9	26.4	21.8
	8-9	25.5	10.3	2.9	9.5	14.0
	10+	32.3	25.2	1.1	7.8	20.7
	Mean	8.5	7.4	4.4	6.0	7.1
3	<b>Monthly Family Income (in Rs.):</b>					
	Less than 5000	0.6	43.8	31.4	33.7	25.6
	5001-10000	2.6	16.6	51.7	12.9	17.0
	10001-15000	1.7	4.6	6.4	3.4	3.7
	15001-20000	0.3	4.6	1.7	1.1	2.1
	More than 20001	0.3	8.9	1.7	1.1	3.5
	No answer	94.6	16.3	7.0	47.8	46.3
	No income	0.0	5.2	0.0	0.0	1.7
	Mean	11631.5	12362.9	7237.2	6146.2	

With regard to data on the family income of the respondents, less than half (46.3%) of them did not answer, followed by a quarter (25.6%) of them whose family income is less than Rs.5000 while 17.0 per cent of the respondents have family incomes between Rs.5001 and 100000. Very few (3.7%) of the respondents have family incomes between Rs.10001 and 15000.

District-wise variations were seen with a majority (94.6%) of the respondents from Jaipur not revealing their family income, while 47.8 per cent, 16.3 per cent and 7.0 per cent respondents from Amritsar, Nashik and Madurai respectively did not reveal information about the same. Slightly more than half (51.7%) of the respondents from Madurai have a family income in the Rs.5001-10000 income bracket, while 16.6 per cent respondents from Nashik and 12.9 per cent

of them from Amritsar are in the same income range. Very few (2.6%) of the respondents from Jaipur have family incomes between Rs.5001-10000.

More or less similar proportions of respondents in the study districts have family incomes less than Rs.5000. Less than half (43.8%) of the respondents from Nashik belong to this category, as do 33.7 per cent respondents from Amritsar and 31.4 per cent of them from Madurai. The mean family income is Rs.12, 362 in Nashik, Rs.11,631 in Jaipur, Rs.7, 237 in Madurai and Rs.6, 146 in Amritsar.

### **SIMILAR DISABILITY IN THE FAMILY**

In terms of whether the patients' family members have had any similar disabilities, a majority (92.6%) of the respondents in general do not have family members with similar disabilities. Similarly, in all the districts, significant proportions of respondents state the same.

**Table 4.2: Similar Disability in the Family**

<b>Whether similar disability in the family</b>		<b>Jaipur N=348</b>	<b>Nashik N=327</b>	<b>Madurai N=165</b>	<b>Amritsar N=172</b>	<b>Total N=1012</b>
No		97.2	93.4	92.9	81.5	92.6
Yes	Male	0.9	3.4	1.2	2.2	2.0
	Female	0.3	2.9	2.9	1.1	1.7

Overall, very few (2.0% and 1.7%) of the male and female respondents respectively say that their family members do not have similar disabilities. About 3.4 per cent of the male respondents in Nashik have family members who have similar disabilities. Nashik and Madurai have the same number of female respondents who have family members with similar disabilities at 2.9 per cent each. Among male respondents, about 2.2 per cent, 1.2 per cent and 0.9 per cent of them from Amritsar, Madurai and Jaipur respectively report that their family members have similar disabilities, while among female respondents, 1.1 per cent and 0.3 per cent respondents state the same.

In terms of family background of the persons with cleft lip/palate, a small proportion of respondents with the disability are living in single person households, a trend that is not seen in the earlier study. While family size is more or less the same, the proportion of respondents in the more than Rs.5000 family income is also seen as an emerging trend indicating improving economic conditions of the families.

## Chapter 5

### Background of Mothers

In order to understand the possible factors contributing to the occurrence of cleft lips and/or palates, information about the respondents' mothers was collected and the same is presented here.

#### TYPE OF MARRIAGE

Non-consanguineous marriages of mothers are seen among less than half (44.3%) of the respondents. Across districts, the largest (96.0%) proportion of respondents from Jaipur state non-consanguineous marriages, followed by 38.2 per cent of them from Madurai who state the same while less than a quarter (23.0%) of the respondents report non-consanguineous marriages with a few (5.7%) of the respondents from Nashik reporting the same.

**Table 5.1: Background of Mothers**

S.No	Mother's Background	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
1	Consanguineous	3.1	2.9	1.2	0.0	2.2
	Non-consanguineous	96.0	5.7	38.2	23.0	44.3
	Not specified	0.9	91.4	60.6	77.0	53.5
2	<b>Number of conceptions:</b>					
	1	0.3	1.1	5.3	1.7	1.6
	2	4.3	1.4	9.4	2.8	3.9
	3	2.3	2.3	4.1	4.5	3.0
	4	0.3	1.1	1.8	1.7	1.0
	More than 5	0.60	0.60	2.40	1.20	1.0
	Mean	2.7	2.8	2.5	2.9	2.7
3	<b>Pre-natal complications:</b>					
	Anaemic	2.3	0.0	1.8	3.9	1.7
	Fever	1.7	2.0	11.8	1.7	3.4
	Accident	0.0	0.6	1.2	.0	0.4
	Intake of drugs	0.0	0.0	1.2	.6	0.3
	Ill health	0.3	0.9	7.6	.0	1.6
	Others	62.4	71.3	2.9	28.7	50.0
	No complications	33.3	25.2	73.5	65.2	42.6



Overall, data on the number of conceptions of the mothers of cleft patients, few (3.9% and 3.0%) of the respondents report 2 and 3 conceptions with 1.6 per cent and 1.0 per cent respondents each reporting 1, 4 and more than 5 conceptions. Across districts, 9.4 per cent of respondents from Madurai conceived twice, followed by 5.3 per cent of them from the same district who conceived once while 4.5 per cent, 4.3 per cent and 4.1 per cent of the respondents from Amritsar, Jaipur and Madurai respectively report 3, 2 and 3 conceptions respectively. Two, more than 5 and 3 conceptions are reported by very few (2.8%, 2.4% and 2.3% each) of the respondents from Amritsar, Madurai, Nashik and Jaipur respectively. The mean number of conceptions among respondents is 2.7 overall and are 2.9 for Amritsar, 2.8 for Nashik, 2.7 for Jaipur and 2.5 for Madurai.

With respect to reporting on pre-natal conceptions among the mothers, half (50.0%) of the respondents report other pre-natal complications, while 42.6 per cent of the mothers had no pre-natal complications. Fever, anaemia and ill health are reported by few (3.4%, 1.7% and 1.6%) as some of the pre-natal complications. District wise data reveal that almost three-fourth (73.5% and 71.3%) of the respondents Madurai and Nashik report no complications and other pre-natal complications respectively. More than half (65.2%) of the respondents from Amritsar report no complications. About 62.4 per cent of them from Jaipur report other complications. About 28.7 per cent of the respondents from Amritsar report other complications while quarter (25.2%) of them report no complications. A few (11.8%) of the respondents from Madurai report fever while 3.9 per cent of them from Amritsar report anaemia and 2.3 per cent of respondents from Jaipur report the same pre-natal complication.

A major drop is seen among the type of marriage patterns of the mothers of the cleft lip/palate patients with the number of consanguineous marriages at a mere 2.2 per cent as compared to the 29.8 per cent such cases reported in 2000. The number of conceptions is also seen to decline steadily. Further, a decline is also observed in the number of pre-natal complications from the earlier study which shows improved access to health care facilities, particularly with regard to maternal health and pre-natal care. This is also reiterated by the less than half proportion of no pre-complications among the mothers of the cleft lip/palate patients.

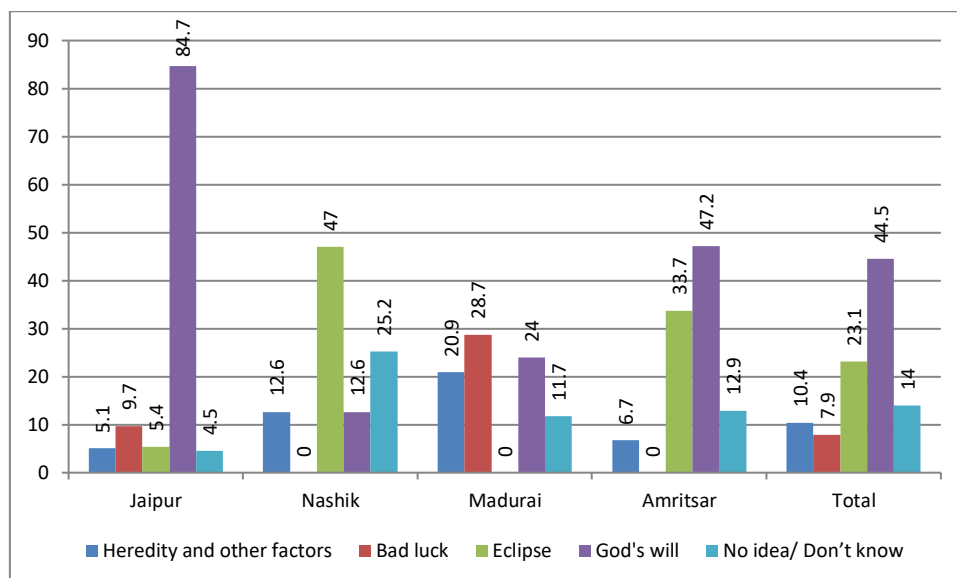
## Chapter 6

# Perceived Causes, Earlier Efforts and Readiness for its Correction

The present chapter covers the perception of the respondents with reference to the causes of cleft lips and/or palates, earlier efforts to correct the disability and readiness to correct it.

### PERCEPTIONS ABOUT THE DISABILITY

Less than half (44.5%) of the total respondents perceive cleft lips and/or palates to be a result of God's will. Less than a quarter (23.1%) of them state that the disability is a result of an eclipse, while a few (14.0%) of them do not know the cause of the disease. One-tenth (10.4%) of the respondents blame it on heredity and factors like negligence, physical or physiological problems, past birth karma and other superstitious beliefs and 7.9 per cent of the respondents say that the disease is a result of bad luck. District-wise variations are seen in the same regard with Jaipur showing the highest (84.7%) proportion of respondents who state God's will as a cause of the disability while Amritsar and Nashik show similar proportions (47.2% and 47.0% respectively) of respondents who report God's will and eclipses respectively as perceived causes of the disability.



About 33.7 per cent respondents from Amritsar perceive that the disability is caused by an eclipse, followed by 28.7 per cent of the respondents from Madurai who perceive bad luck as a cause of the disability while a quarter (25.2%) of the respondents in Nashik who do not know the cause with 24.0 per cent respondents in the same district who perceive the disability as a result of God's will. The same perceived cause is reported by 12.6 per cent respondents in Nashik. Similar proportions of respondents in Amritsar (12.9%) and Madurai (11.7%) of the respondents do not know the cause of the disability. Few (9.7% and 5.4%) of the respondents from Jaipur state perceived causes such as bad luck and eclipses respectively while 4.5 per cent of them from the same district do not know the cause of the disability.

A respondent's mother recalls:

*When my daughter was born with cleft lip, my mother-in-law put all the blame on me and sent me back to my mother's house. Thanks to the free surgery option given by Smile Train that I got my pride in family"*

**Table 6.1: Perceptions about Disability\***

S.No	Perceived Causes, Earlier Efforts and Readiness	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
<b>1</b>	<b>Perception about disability:</b> Heredity and other factors	5.1	12.6	20.9	6.7	10.4
	Bad luck	9.7	0.0	28.7	0.0	7.9
	Eclipse	5.4	47.0	0.0	33.7	23.1
	God's will	84.7	12.6	24.0	47.2	44.5
	No idea/ Don't know	4.5	25.2	11.7	12.9	14.0
<b>2</b>	<b>Earlier efforts made:</b> No efforts made	25.6	6.6	1.2	8.4	12.4
	Uncertain	1.1	0.0	1.2	0.0	0.6
	Had an operation	51.9	93.4	85.4	77.5	75.5
<b>3</b>	<b>Readiness to correct disability:</b> Yes	74.3	56.7	30.0	43.3	56.0

\*Multiple responses are possible

With regard to the earlier efforts made to correct the disability, three-fourth (75.5%) of the respondents overall had operations, followed by a little over one-tenth (12.4%) of them who did not make any such efforts. Districts showed no variations in this regard with majority of the respondents across all of them having operations viz., 93.4 per cent in Nashik, 85.4 per cent

in Madurai and 77.5 per cent Amritsar. However, only a little over half (51.9%) of the respondents in Jaipur report that they had operations while 25.6 per cent respondents in the same district did not make any efforts.

A respondent’s mother says:

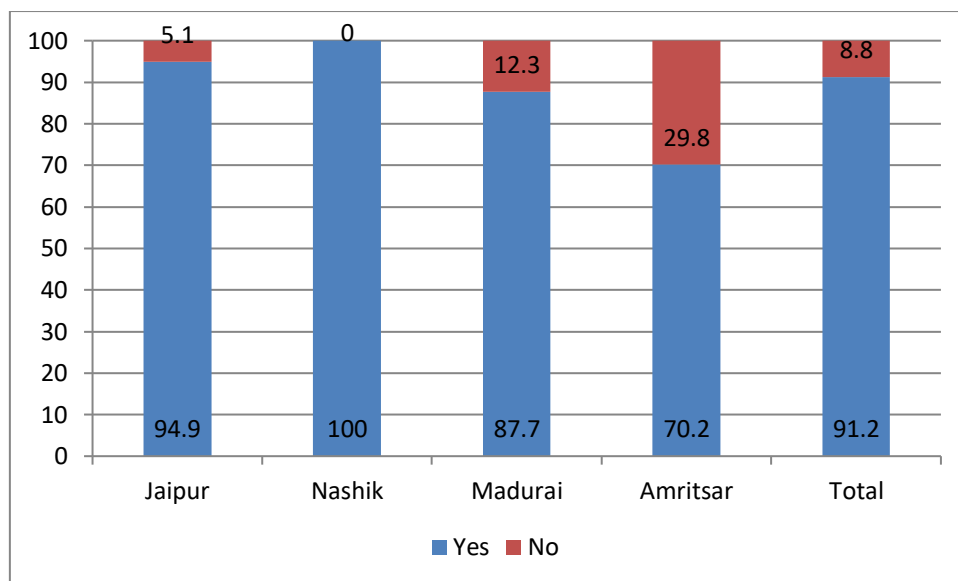
*“I can recall the agony and pain we have suffered when our first son, who was also born with cleft lip, died within a few days of his birth because I could not feed him because of his cleft lip. When my daughter was born with the same defect we were very stressed, but today my daughter is alive because of Smile Train’s free operation”*

In general, 56.0 per cent respondents show readiness to correct the disability if provided with the opportunity to do so. Among districts, Jaipur shows the most (74.3%) respondents with the readiness to correct the disability followed by those in Nashik (56.7%) showing readiness for the same while 43.3 per cent and 30.0 per cent of the respondents from Amritsar and Madurai respectively stating the same.

## KNOWLEDGE ABOUT CORRECTIONS OF THE CLEFT

**Table 6.2: Knowledge about cleft correction**

	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Yes	94.9	100.0	87.7	70.2	91.2
No	5.1	-	12.3	29.8	8.8



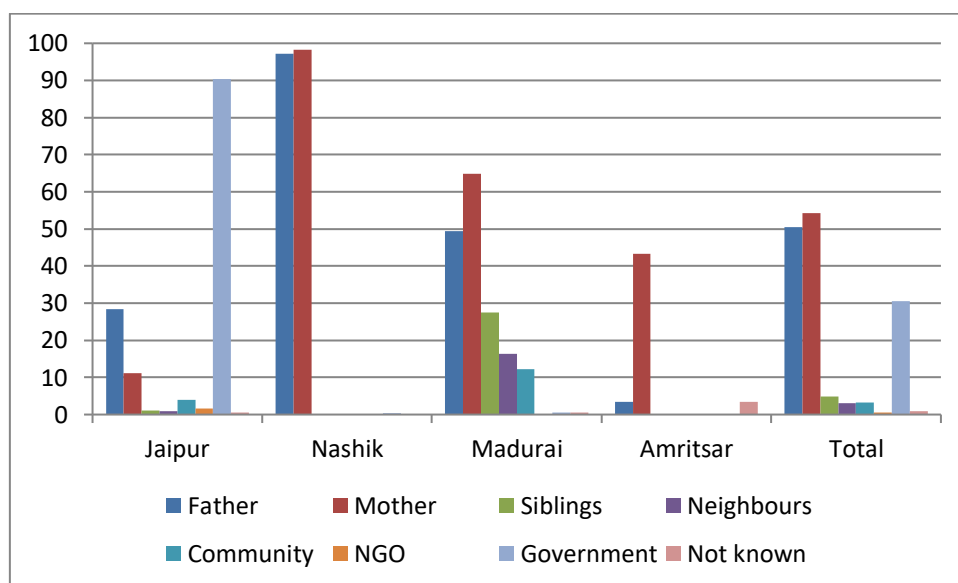
In general, respondents know that cleft lips and palates can be corrected with a majority (91.2%) of them stating the same. All of the respondents in Nashik know about cleft corrections. Jaipur ranks second in this regard with 94.9 per cent of the respondents stating the same, followed by 87.7 per cent respondents from Madurai and 70.2 per cent of them in Amritsar reporting knowledge about cleft corrections. A qualitative analysis reveals that most respondents became aware about cleft corrections through Smile Train camps, advertisements in newspapers or at the local Primary Health Centre (PHC), doctors, family members or other community members who had corrective surgeries or corrected surgeries.

## VIEWS ABOUT CARE OF DISABLED

**Table 6.3: Perception about who should provide care**

Who should provide such care	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
Father	28.4	97.1	49.4	3.4	50.4
Mother	11.1	98.3	64.9	43.3	54.3
Siblings	1.1	0.0	27.5	0.0	4.9
Neighbours	0.9	0.0	16.4	0.0	3.0
Community	4.0	0.0	12.3	0.0	3.3
NGO	1.7	0.0	0.0	0.0	0.6
Government	90.3	0.3	0.6	0.0	30.5
Not known	0.6	0.0	0.6	3.4	0.9

\*multiple responses are possible



With regard to the perceptions of the respondents as to who should provide care to such disabled persons, more than half (54.03%) of them believe it should be mothers, followed by 50.4 per cent of them say it should be fathers while more than a quarter (30.5%) of the respondents say it should be the government through special schemes and support. District-wise a majority (98.3%) of the respondents from Nashik report mothers should be care givers followed by 97.13 per cent of them from the same district who report fathers should be the care givers. More than half (64.9%) of the respondents from Madurai say that mothers should take care of such persons, followed by 43.3 per cent respondents from Amritsar who state the same.

Beliefs about the perceived cause of the disability remain more or less the same; however, far less numbers of respondents now state that they know nothing about the disability. Effective intervention in correcting the disability prominently shows through the difference of almost 34.0 per cent, seen in the present study (12.4%) and the earlier study (46.1%) among those who did not make any efforts to correct it. It is significant to note that a rise is seen among those who already had corrective surgery. Earlier, this category consisted of only a quarter respondents, however, in the present study, almost three-fourth (75.5%) respondents report to already being operated.

## Chapter 7

### Incidence of Cleft Lip and/or Palate

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Incidence rates provide an estimate of the incidences of cleft lip and/or palates in a given population. Studies carried out in different parts of the world help place India in a global scenario with regard to incidences of cleft lips and/or palates. For instance, in the United States of America (USA), the incidence rate for cleft lip with or without cleft palate is 2.2 to 11.7 per 10,000 live births while that of cleft palate is 5.5 to 6.6 per 10,000 births (0.2 to 1.1 per 1000 live births, 0.5 to 0.6 per 1000 live births respectively). When discussing the incidence of cleft lip and/or palates in different cultures, studies found that the incidence rate for cleft lip with or without cleft palate in Hawaii were highest at 16 persons per 10,000 births among people of Far East Asian descent, 14.5 among people of Filipino descent, 11 among the Pacific Islanders and 10 persons among Caucasians. Similar analyses in Jordan revealed that the incidence rate for cleft lip with or without cleft palate over a period of 11 years was 1.39 per 1,000 live births. Studies exploring the countries of origin of the persons with cleft lips and/or palates found higher incidence rates for Asians, specifically in Pakistan, with the prevalence rate at 1.91 per 1,000 live births while a similar incidence rate of 1.81 per 1,000 live births were seen in the Republic of Korea<sup>8</sup>.

Against this backdrop, incidence rates for the study districts and the country as a whole are also worked out and estimates for the same are presented here. It is expected that incidence rates will help give some direction and placement for timely intervention in the concerned areas.

**Table 7.1: District-wise Incident Rate of Cleft Cases**

District	Incidence Rate of Cleft Cases
Jaipur	One in 5882 live births
Nashik	One in 3448 live births
Madurai	One in 4545 live births
Amritsar	One in 3030 live births
<b>Total</b>	<b>One in 4762 live births</b>
<b>India</b>	<b>One in 4952 live births</b>

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<sup>8</sup> [http://en.wikipedia.org/wiki/Clefting\\_prevalence\\_in\\_different\\_cultures](http://en.wikipedia.org/wiki/Clefting_prevalence_in_different_cultures) Wikipedia.org

## NASHIK

Based on the age distribution of the cleft cases in the study districts and other relevant demographic indicators, the incidence rate of cleft cases are calculated and they are as follows:

District	Incidence Rate of Cleft Cases
Nashik	One in 3448 live births

### Method of Calculating Incidence rate of Cleft Cases

Considering Nashik survey data as basic information, the following method has been adopted.

Population of Nashik District (India, 2011): 6107187

Total number of cleft cases (Nashik): 349

Number of cleft cases enumerated under 1year age(Nashik): 22 cases

Assuming that the same number of cleft cases prevail for each year upto four years of age, estimated

Number of cleft cases in 0---4 yrs age group (Nashik)= $22 \times 4 = 88$

The survey data reveals that the cleft cases in 0---4 yrs age group

22 (of < 1yr) +98 (of 1---4yrs)(Nashik) = 120 cases.

120 cases prevailed at the time of Survey and the remaining(enumerated(120) -expected(88)) 32 cases.

This, in turn, indicates that 6 deaths have occurred among the cleft cases, per year, on an average. For the current year, applying the correction factor of the cleft cases, the total number of cleft cases in the age group of 0---1 year is expected to be:

$22(\text{enumerated cases}) + 8(\text{expected deaths among the cleft cases}) = 30 \text{ cases} \text{ ----(1)}$

The number of live births for the Nashik District as a whole is reported to be:

105260 per year.----(2)

Therefore, the **Incidence Rate** of cleft cases in Nashik District in the age group of 0---1 yr.

$(1)/(2) * 1000$

That is, Incidence rate =  $(30/105260) * 1000$

=0.29 case per 1000 live births

In other words, 1 cleft case per 3448 live births

## JAIPUR

Based on the age distribution of the cleft cases in the study districts and other relevant demographic indicators, the incidence rate of cleft cases are calculated and they are as follows:

District	Incidence Rate of Cleft Cases
Jaipur	One in 5882 live births

### Method of Calculating Incidence rate of Cleft Cases

Considering the Jaipur survey data as basic information, the following method has been adopted.



Population of Jaipur District(India,2011):6626178

Total number of cleft cases(Jaipur):352

Number of cleft cases enumerated under 1 year age(Jaipur):13 cases

Assuming that the same number of cleft cases prevail for each year up to four years of age, estimated

Number of cleft cases in 0---4 yrs age group(Jaipur) = $13 \times 4 = 52$

The survey data reveals that the cleft cases in 0---4 yrs age group

13(of < 1 yr) +122(of 1---4yrs)(Jaipur) = 135 cases

135 cases prevailed at the time of Survey and the remaining(enumerated(135) -expected(52)) =83 cases.

This, in turn, indicates that 21 deaths have occurred among the cleft cases, per year, on an average. For the current year, applying the correction factor of the cleft cases, the total number of cleft cases in the age group of 0---1 year is expected to be:

$13(\text{enumerated cases}) + 21(\text{expected death among the cleft cases}) = 34 \text{ cases} \text{-----}(1)$

The number of live births for the Jaipur District as a whole is reported to be:

190390 per year.----(2)

Therefore, the **Incidence Rate** of cleft cases in Jaipur District in the age group of 0---1 yr.

$(1)/(2) * 1000$

That is, Incidence rate = $(34/190390) * 1000$

=0.17 case per 1000 live births

In other words, 1 cleft case per 5882 live births

## **MADURAI**

Based on the age distribution of the cleft cases in the study districts and other relevant demographic indicators, the incidence rate of cleft cases are calculated and they are as follows:

District	Incidence Rate of Cleft Case
Madurai	One in 4545 live births

### **Method of Calculating Incidence rate of Cleft Cases**

Considering the Madurai survey data as basic information, the following method has been adopted.

Population of Madurai District(India,2011):3038252

Total number of cleft cases(Madurai):172

Number of cleft cases enumerated under 1 year age(Madurai):2

Assuming that the same number of cleft cases prevail for each year upto four years of age, estimated

Number of cleft cases in 0---4 yrs age group (Madurai)= $2 \times 4 = 8$

The survey data reveals that the cleft cases in 0---4 yrs age group

$$4(\text{of } < 1\text{yr}) + 44 (\text{of } 1\text{---}4\text{yrs})(\text{Madurai}) = 48$$

48 cases prevailed at the time of Survey and the remaining(enumerated(48) -expected(16)) =32 cases.

This, in turn, indicates that 8 deaths have occurred among the cleft cases, per year, on an average.

For the current year, applying the correction factor of the cleft cases, the total number of cleft cases in the age group of 0---1 year is expected to be:

$$4(\text{enumerated cases}) + 8(\text{expected deaths among the cleft cases}) = 12 \text{ ----(1)}$$

The number of live births for the Madurai District as a whole is reported to be:

$$53073 \text{ ----(2)}$$

Therefore, the **Incidence Rate** of cleft cases in Madurai District in the age group of 0---1 yr.

$$(1)/(2) * 1000$$

$$\text{That is, Incidence rate} = (12/53073) * 1000$$

$$= 0.22 \text{ case per } 1000 \text{ males}$$

In other words, 1 cleft case per 4545 live births

## AMRITSAR

Based on the age distribution of the cleft cases in the study districts and other relevant demographic indicators, the incidence rate of cleft cases are calculated and they are as follows:

District	Incidence Rate of Cleft Case
Amritsar	One in 3030 live births

### Method of Calculating Incidence rate of Cleft Cases

Considering the Amritsar survey data as basic information, the following method has been adopted.

Population of Amritsar District(India,2011):2490656

Total number of cleft cases(Amritsar):178

Number of cleft cases enumerated under 1 year age(Amritsar):3

Assuming that the same number of cleft cases prevail for each year upto four years of age, estimated

$$\text{Number of cleft cases in } 0\text{---}4 \text{ yrs age group (Amritsar)} = 3 * 4 = 12$$

The survey data reveals that the cleft cases in 0---4 yrs age group

$$3(\text{of } < 1\text{yr}) + 32 (\text{of } 1\text{---}4\text{yrs})(\text{ Amritsar}) = 35$$

35 cases prevailed at the time of Survey and the remaining (enumerated(35) -expected(12)) =47 cases.

This, in turn, indicates that 12 deaths have occurred among the cleft cases, per year, on an average.

For the current year, applying the correction factor of the cleft cases, the total number of cleft cases in the age group of 0---1 year is expected to be:

$$3(\text{enumerated cases}) + 12(\text{expected deaths among the cleft cases}) = 15 \text{ -----(1)}$$

The number of live births for the Amritsar District as a whole is reported to be:

$$45081 \text{ -----(2)}$$

Therefore, the **Incidence Rate** of cleft cases in Amritsar District in the age group of 0---1 yr.

$$(1)/(2) * 1000$$

$$\begin{aligned} \text{That is, Incidence rate} &= (15/45081) * 1000 \\ &= 0.33 \text{ case per 1000 males} \end{aligned}$$

In other words, 1 cleft case per 3030 live births

### **INCIDENCE RATE OF CLEFT CASES: Total**

Based on the age distribution of the cleft cases in the study districts and other relevant demographic indicators, the incidence rate of cleft cases are calculated and they are as follows:

District	Incidence Rate of Cleft Case
Total	One in 4762 live births

### **Method of Calculating Incidence rate of Cleft Cases**

Considering the Total survey data as basic information, the following method has been adopted.

Total number of cleft cases(Total):1051

Number of cleft cases enumerated under 1 year age(Total):42

Assuming that the same number of cleft cases prevail for each year upto four years of age, estimated

Number of cleft cases in 0---4 yrs age group (Total)=42\*4=168

The survey data reveals that the cleft cases in 0---4 yrs age group

$$42(\text{of } < 1\text{yr}) + 285 (\text{of } 1\text{---}4\text{yrs})(\text{Total}) = 327$$

327 cases prevailed at the time of Survey and the remaining(enumerated(327) -expected(168)) =159 cases . This, in turn, indicates that 40 deaths have occurred among the cleft cases, per year, on an average.

For the current year, applying the correction factor of the cleft cases, the total number of cleft cases in the age group of 0---1 year is expected to be:

$$42(\text{enumerated cases}) + 40(\text{expected deaths among the cleft cases}) = 82 \text{ -----(1)}$$

The number of live births for the all the selected Districts as a whole is reported to be:

$$393804 \text{ -----(2)}$$

Therefore, the **Incidence Rate** of cleft cases in all the selected Districts in the age group of 0---1 yr.

$(1)/(2) * 1000$

That is, Incidence rate  $= (82/393804) * 1000$

$= 0.21$  case per 1000 males

In other words, 1 cleft case per 4762 live births

With regard to the incidence rate among the respondents with cleft lip/palate in the study locations, a decline is seen when compared with data from the earlier study. For instance, the incidence rate in Nashik district currently stands at one in 3448 cases from one in 990 live births. Similarly, among the other districts, the incidence rate of cleft lips and/or palates is seen to be declining. This highlights the improved intervention with regard to reaching the persons with cleft lips and/or palates. It also points to the fact that such persons now have better access to facilities and medical services that will help timely correction of the disability. Such factors will have a positive impact on the inclusion of such persons in the mainstream society and will improve their economic well-being in the society.

## Chapter 8

### Details about Correction of Cleft Lip and/or Palate

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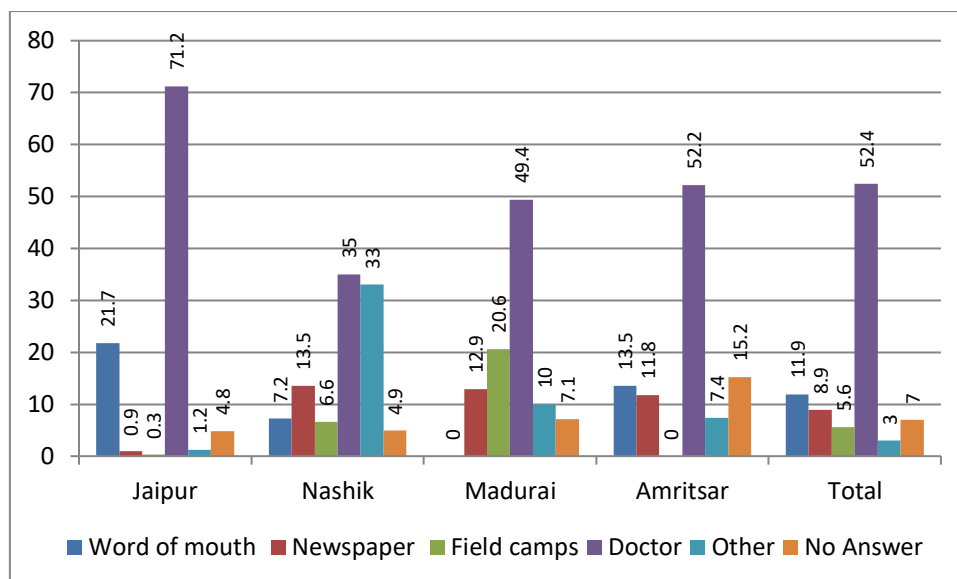
Respondents were also asked about the information they had about the surgery. In addition, their experiences during and after their surgery were also analysed and are presented here.

#### INFORMATION ABOUT CORRECTIVE SURGERIES OF CLEFT LIPS/PALATE

Out of 1051 respondents contacted during this research almost all (91.2%) the respondents are aware about the possibility of surgical correction of Cleft lip / Palate. Only 8.8 per cent of respondents state that they do not have any information about corrective measures.

**Table 8.1: District-wise sources of information**

Sources	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
Word of mouth from similarly affected patients	21.7	7.2	0.0	13.5	11.9
Newspaper advertisement	0.9	13.5	12.9	11.8	8.9
Social Worker	0.3	0.6	3.5	0.6	1.0
Field camp by Smile train partner	0.3	6.6	20.6	0.0	5.6
Muskan Utsav	0.0	0.3	0.0	0.6	0.2
From a doctor	71.2	35.0	49.4	52.2	52.4
Outreach staff of Smile train partner	0.0	1.4	2.4	0.0	0.9
Other	0.9	30.7	4.1	6.2	0.9
No Answer	4.8	4.9	7.1	15.2	7.0



People are learning about treatment possibilities from a variety of sources such as word of mouth, doctors and newspaper ads. However, doctors are most popular source among all as 52.4 per cent of respondents state that came to know about the corrective option through doctors only. This is followed by word of mouth and 11.9 per cent respondents say that they got the information from parents of the patients. Advertisements in the newspapers are emerging as the next prominent source of information and 8.9 per cent respondents report that they benefited by these ads. Field camps organised by Smile Train from time to time are significant avenues responsible for awareness among the respondents, which 5.6 per cent respondents mention. Other sources include social workers (1.0%), Muskan Utsav (0.20%), and outreach efforts by the staff of Smile Train (0.9%).

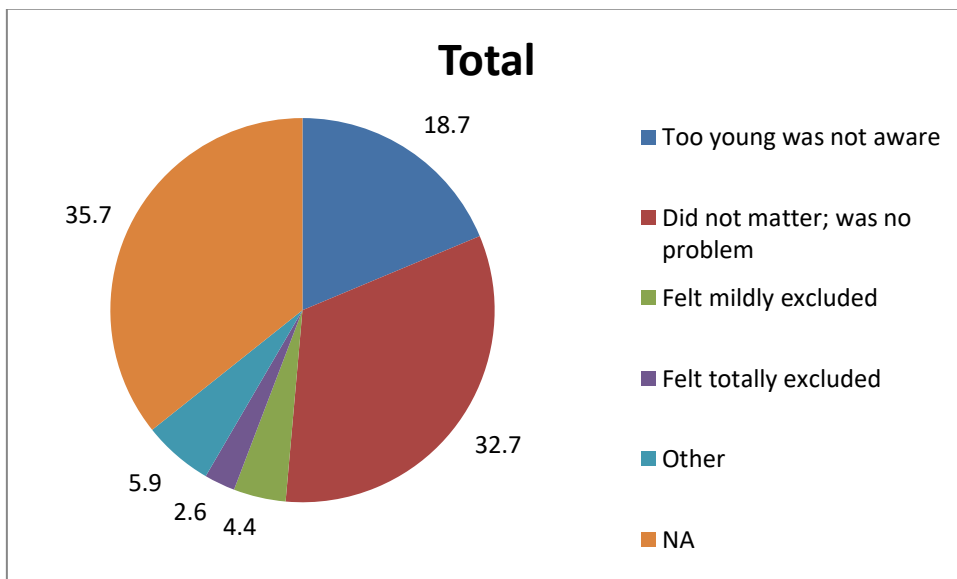
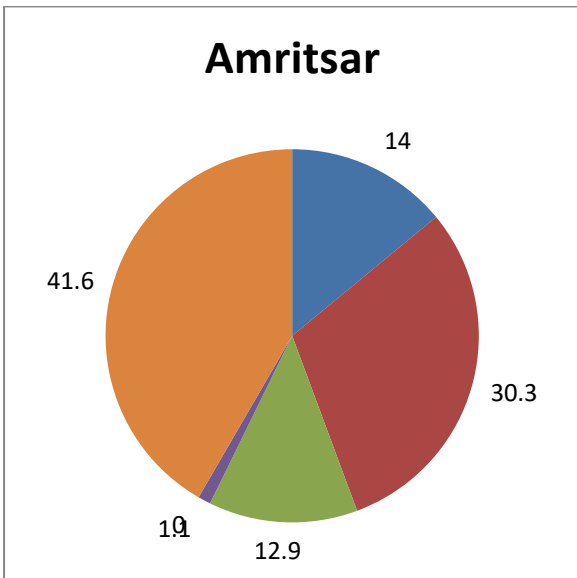
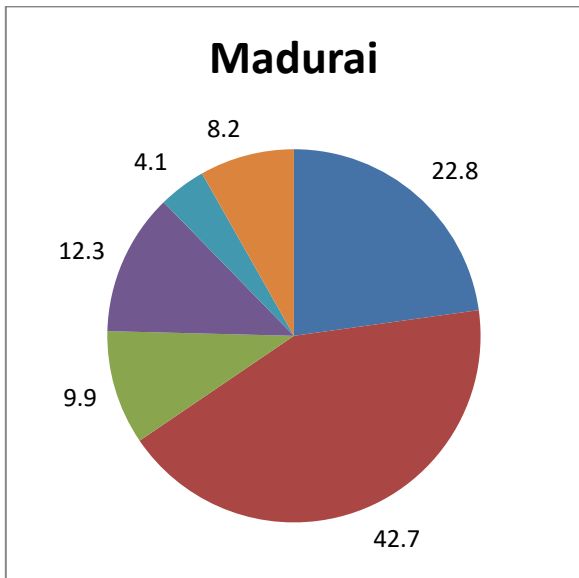
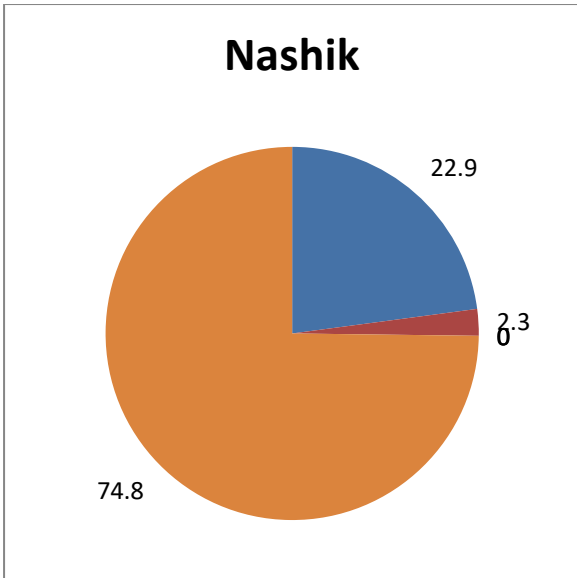
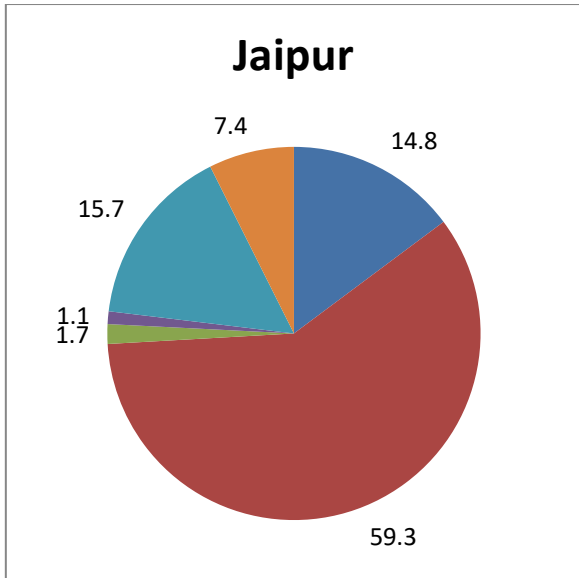
District-wise picture is somewhat different from aforementioned scenario. Doctors continue to remain a major source of awareness among people in all the districts covered during the survey with 71.2 per cent respondents from Jaipur, 52.2 per cent in Amritsar, 49.4 per cent in Madurai and 35.0 per cent in Nashik expressing the same. However, data indicate that second most popular information source varies across the districts with 13.5 per cent respondents in Amritsar and 21.7 per cent of them in Jaipur who report word of mouth to be their most significant information source. But, respondents of Madurai (21.0%) report being reached via the field camps organised by Smile Train. Similarly, respondents in Nashik district (30.7%) consulted others sources and only 7.2 per cent of them from the same district got the information through word of mouth. Newspaper advertisements have surfaced as the third major source of awareness among respondents of all the districts covered during the research.

But the share of utilising this resource varies amongst the surveyed districts. In Jaipur, the newspaper emerges as the third most common source but only 0.9 per cent respondents were reached by these ads. The success of ads is far better in other places with 13.5 per cent respondents in Nashik, 13.0 per cent in Madurai and 11.8 per cent in Amritsar who mention newspaper advertisements as information sources about the Smile Train program.

Field camps organised by Smile Train in association with the treatment centers are also playing a very significant role in spreading awareness about the available treatment of the people born with Cleft lip/Palate as well as the free surgery program run by Smile Train. These camps are very significant especially for people who inhabit remote areas because other major sources such as newspapers fail to reach that population. But in some districts due to some local reasons these camps are not the first point of contact, such as in Amritsar no respondent mentioned these field camps and in Jaipur, only 0.3 per cent respondents have attended these camps whereas in Madurai, 21.0 per cent and 6.6 per cent in Nashik report these camps as their prime information source. However, special programs to disseminate information about this congenital defect such as outreach staff of Smile Train partner institutions (sometimes referred to as Public Relation Officer) and Muskan Utsav failed to have any substantial impact on people. Social workers are also helping disperse the information related to the program but the level of participation is different in different districts viz., Jaipur (0.3%), Nashik (0.6%), Madurai (4.0%) and Amritsar (0.6%).

### **AWARENESS AND FEELINGS BEFORE SURGERY**

In this section, an attempt is made to capture the awareness and feelings before the surgery among Cleft lip/palate Patients as well as their families. This section is significant as it will provide insights into the challenges faced by people born with cleft lip/palate in India. Patients as well as their families, especially mothers, are found to experience a variety of discrimination due to this congenital defect.





**Table 8.2: District wise patient’s awareness and feelings before surgery**

<b>Awareness and feelings about surgery</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Too young was not aware	14.8	22.9	22.8	14.0	18.7
Did not matter; was no problem	59.3	2.3	42.7	30.3	32.7
Felt mildly excluded	1.7	0.0	9.9	12.9	4.4
Felt totally excluded	1.1	0.0	12.3	1.1	2.6
Other	15.7	0.0	4.1	0.0	5.9
NA	7.4	74.8	8.2	41.6	35.7

People born with cleft lip/palate experience different forms of difficulties related to aesthetic as well as functional problems. About 33.0 per cent of surveyed patients report not having faced any problem due to this defect while 36.0 per cent patients did not answer this question. Only 2.0 per cent of them are able to gather the courage to express freely that they feel totally excluded from the society and 4.0 per cent feel mildly excluded. Few (6.0%) of the respondents report to facing other kinds of discrimination. It should be noted that around 19.0 per cent of the patients contacted were too young to express themselves.

District wise data show the aforementioned trends. More than half (59.3%) of the respondents in Jaipur feel cleft lip/palate is not a problem for them followed by those from Madurai (42.7%), Amritsar (30.3%) and Nashik (2.3%). Three-fourth (74.8%) respondents in Nashik and Amritsar (41.6%) did not answer. However, the corresponding figures in Jaipur (7.4%) and Madurai (8.2%) are comparatively less. It is evident from the data that significant number of respondents are too young to answer the question, viz., Nashik (22.9%), Madurai (22.8%), Jaipur (14.8%) and Amritsar (14.0%). The proportion of respondents who report to be subjected to either mild or total exclusion is very low as compared to those who feel completely normal across all the districts. Few (12.9%, 9.9% and 1.7%) from Amritsar, Madurai and Jaipur feel mildly excluded because of their cleft lip/palate while 12.3 per cent and 1.1 per cent respondents each from Madurai and Amritsar and Jaipur respectively report feeling totally excluded.

## MOTHER/FAMILY'S AWARENESS AND FEELINGS

**Table 8.3: District wise mother /family's awareness and feelings**

<b>Mother/family's awareness and feelings</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Had full family/peer support	6.8	91.4	43.9	43.8	47.3
Looked down upon	83.8	0.0	25.1	3.9	32.8
Taunted but accepted	0.9	0.3	7.0	11.8	3.5
Abandoned and excluded	0.0	0.0	2.3	1.1	0.6
Other	3.7	0.0	1.2	21.3	5.1
NA	4.8	8.3	20.5	18.0	10.8

Analysis of the data on the awareness and feelings of the mothers/family members of the cleft lip/palate patients reveals that less than half (47.3%) of the respondents report that they have full family/peer support. However, 32.8 per cent of the respondents, especially mothers of the patients, state that they were looked down upon by people as well as by their own family members while 3.5 per cent of them report being taunted initially but being accepted by others later. Some of the mothers reveal that they were blamed for giving birth to a child with cleft lip/palate due to some bodily deficiencies.

About 5.1 per cent respondents experience other sorts of discrimination. However, only 0.6 per cent of them report abandonment and exclusion. District wise analysis of data reveals that majorly, respondents have complete support from their family and peers. Across all the districts, a fairly high percentage of people (Nashik- 91.4%, Madurai-43.9% and Amritsar-43.8%) expressed to have family support when their child/children are born with this congenital defect but in Jaipur, a large number of people (83.8%) report that they are disrespected and only 6.8 per cent of them got the support of families and peers.

## INFORMATION ABOUT SURGERY

Distance from medical facilities is one of the most critical factors for success or failure of any intervention. This section outlines various aspects related to the surgery such as access to the hospital, financial aid and counseling. Analysis of data provides several dimensions related to the whole process of surgery which has the potential to affect the choice of a patient.

**Table 8.4: Distance travelled by patient /family for treatment**

<b>Distance travelled (in kms)</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Less than 5.0	3.4	0.9	7.0	33.7	8.3
5.1-10.0	9.7	0.6	11.6	9.0	6.9
10.1-20.0	23.6	0.6	14.5	8.4	11.9
20.1-30.0	7.4	0.0	18.0	4.5	6.2
30.1-40.0	16.2	0.6	13.4	23.0	11.7
More than 40.1	36.9	8.6	26.7	10.1	21.3
No answer	2.8	88.8	8.7	11.2	33.8
Mean	39.5		28.9	24.8	37.3

Overall, a little over half (51.1%) of the respondents state that they have to travel more than 10 km. About 15.2 per cent respondents have to travel less than 10 kilometers (each side) for the remedial surgeries whereas around. However, a substantial number of respondents, 33.8 per cent, did not respond to this query. The overall mean distance traveled (each side) is 37.3 km.

District-wise analysis highlights different scenarios in different districts. Against an overall average of 21.3 per cent people traveling in excess of 40 km, the corresponding figure in Jaipur is as high as 36.9 per cent and merely 10.1 per cent and 8.6 per cent respectively in Amritsar and Nashik. Amritsar figures prominently for short distances as around 42.7 per cent respondents state that they travel less than 10 km as compared to 1.5 per cent respondents in Nashik. The responses in Madurai are more or less in line with overall averages. One key fact emerges that around 88.8 per cent respondents in Nashik did not respond to this query, thus making any meaningful comparison in its respect difficult. Leaving aside this, the mean distance traveled is almost 40 km in Jaipur whereas it is almost 15 km less in Amritsar at 24.8 km.

**Table 8.5: Admission for treatment on first visit**

<b>Whether patient admitted at first visit</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Yes	85.2	77.9	69.6	69.1	77.5

More than three-fourth (77.5%) respondents report that the patient was admitted for surgery at the first visit to the partner hospital. About 75.5 per cent of them report unfit medical state of

the patient as the reason due to which the hospital refused the treatment at the first visit. Less than a quarter (22.5%) respondents state that they were not admitted when they have visited the treatment centre for the first time. In many cases, as patients are underweight, the doctor was unable to perform corrective operations. Another major reason highlighted by qualitative data is that other patients are already waiting in line for the doctors due to which doctors are unable to attend to the patients immediately. About 20.0 per cent respondents do not know the reason why they are not accepted by the hospital on their first visit. District wise data also show that 15.7 per cent respondents in Amritsar, 14.6 per cent in Madurai, 7.2 per cent in Nashik and 0.3 per cent in Jaipur are not treated due to their unfit medical condition. In Madurai (2.3%) and Nashik (0.3%) respondents report being put on waiting lists as the reason for being declined surgery on the first visit.

**Table 8.6: Waiting time till surgery, after first visit**

<b>Time taken from first visit to surgery</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Less than 15 days	22.8	84.5	67.8	59.6	56.9
16-30 days	0.3	3.2	8.8	5.1	3.4
31-45 days	2.3	2.6	0.0	2.8	2.1
more than 45 days	23.6	3.7	11.1	9.0	12.5
No answer	51.0	6.0	12.3	23.6	25.1
Mean	30.9	10.6	14.8	15.0	16.4

More than half (56.9%) of the respondents report being operated upon in less than 15 days after the first visit to the hospital and 12.5 per cent of them say that they have waited for more than 45 days to receive treatment. District wise data shows the same trends with 84.5 per cent respondents in Nashik, 67.8 per cent in Madurai and 59.6 per cent in Amritsar receive treatment in less than 15 days after their first visit to the treatment centre. But variations can be seen in Jaipur district where only 22.8 per cent people are able to get operated in less than 15 days and an almost equal number of people report waiting for more than 45 days after their first visit to get the treatment. More than half (51.0%) of the respondents in Jaipur are unable to recall the days between their first visit to the hospital and surgery because of being treated a long time ago. The mean waiting time till the surgery after the first visit is 16.4 days overall and is 30.9 days in Jaipur, 15.0 in Amritsar, 14.8 days in Madurai and 10.6 in Nashik.

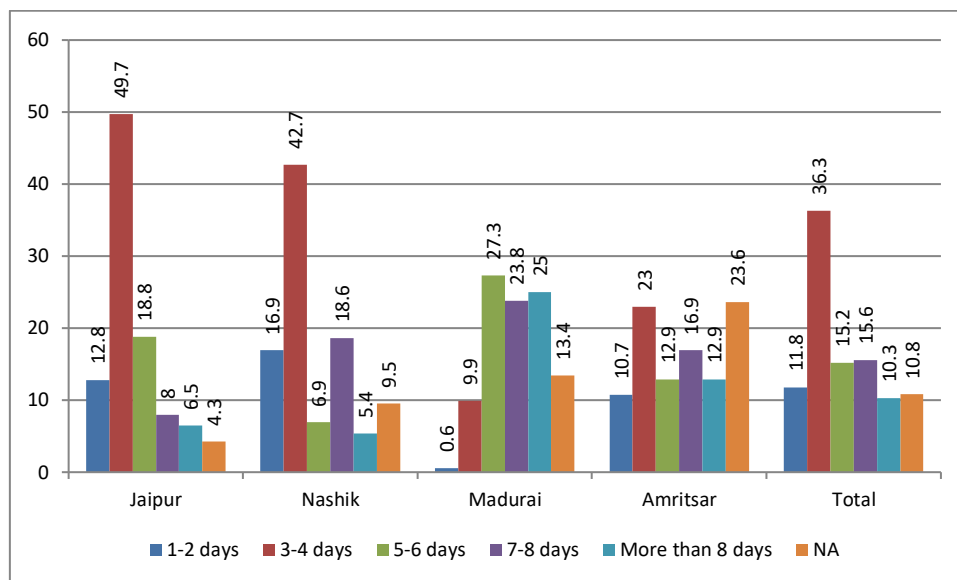
**Table 8.7: Patient received counseling at the first visit**

Whether counseling received	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
Yes	42.5%	81.9%	31.8%	41.0%	53.6%

In response to the question whether patient/parent received any counseling at the first visit to the hospital, more than half (53.6%) of the total respondents state having received counseling at the first visit. On this aspect, the best performing district is Nashik where 81.9 per cent patients are counseled before surgery and Madurai is lacking with only 31.8 per cent respondents admitting to get advice before surgery.

**Table 8.8: Days spent by patient in the hospital**

Number of days spent in hospital	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
1-2 days	12.8	16.9	0.6	10.7	11.8
3-4 days	49.7	42.7	9.9	23.0	36.3
5-6 days	18.8	6.9	27.3	12.9	15.2
7-8 days	8.0	18.6	23.8	16.9	15.6
More than 8 days	6.5	5.4	25.0	12.9	10.3
NA	4.3	9.5	13.4	23.6	10.8
Mean	4.48	4.5	8.2	6.7	5.4



A majority (36.3%) of the respondents report having spent 3-4 days at the hospital at the time of surgery but around one-tenth (10.0%) of them say they have spent more than 8 days in the hospital. Few admit to spending 7-8 days (15.6%), 5-6 days (15.2%) and few even report that they were treated within 1-2 days (11.8%).

District wise analysis shows some variations. In Jaipur 49.7 per cent respondents report having spent 3-4 days in the hospital to get treatment, followed by those who report to have spent 5-6 days (18.8%), 1-2 days (12.8%) and few even state having spent 7-8 days (8.0%) or more than 8 days (6.5%) in the hospital. In Nashik, a majority (42.7%) of the respondents report to having spent 3-4 days. Madurai shows different trends with majority of the respondents staying for more than 5 days to receive the treatment and almost 50.0 per cent of them who report having spent more than a week in the hospital at the time of surgery. In Amritsar as well, a major proportion of the respondents report to being operated on within 3-4 days but around 30.0 per cent of them report to having spent more than 7 days in the hospital.

**Table 8.9: Reimbursement received by patient**

<b>Whether reimbursement received</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
Yes	17.4	16.9	19.4	5.1	15.5
<b>Amount of reimbursement (in Rs.)</b>					
Less than 500	2.6	9.2	1.7	2.2	4.6
501-1000	2.8	4.6	15.1	1.1	5.1
1001-2000	10.5	0.0	2.3	1.1	4.1
More than 2000	1.4	0.6	0.6	0.6	0.9
Other	4.0	4.0	2.0	8.0	18.0
NA	81.5	84.5	79.1	90.4	83.6
Mean	1515.8	572.7	1121	1271.8	1090

Majority of the respondents report to not receiving any financial aid or any kind of reimbursement from hospitals. A small proportion (15.5%) of respondents report having received financial aid. The overall mean of Rs.1090 fails to show the variations. With respect to those who have received reimbursement, merely 0.9 per cent respondents report receiving aid in excess of Rs 2,000 with more than 4.6 per cent respondents receiving less than Rs 500. At mean level, while Amritsar has an average of Rs 1500, Nashik sits low at Rs 570.

## INFORMATION ABOUT POST SURGERY

This section covers feelings and experiences of patient's as well as their families after the corrective surgeries with respect to the speech, looks and adjustment in peer groups. A scale of 1-5 was used with 1 as 'highly dissatisfied' and 5 as 'completely satisfied' with respect to different aspects such as look, speech and overall adjustment in peer group.

**Table 8.10: Patient's Satisfaction (Scale 1 to 5)**

Aspects covered	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
Look	3.7	4.3	3.7	3.3	3.7
Speech	3.6	3.7	3.4	3.2	3.5
Overall adjustment in peer group	4.6	3.7	4.0	2.7 <sup>9</sup>	4.3

Across all the surveyed districts, respondents show high levels of satisfaction in Nashik (4.3), Jaipur and Madurai (3.7 each) and Amritsar (3.3) when it comes to their look after corrective surgery. Satisfaction levels with respect to clarity in the speech of the patient after operation reached almost the same levels as looks across all the districts. The level of satisfaction of patients when it comes to improvement in their ability to adjust in the peer group is almost reaching the level of completely satisfied (4.3) with an exception in Amritsar where 3-5 respondents gave a rating of 2.7 for this parameter.

**Table 8.11: Parents/family's satisfaction (Scale 1 to 5)**

Aspects covered	Jaipur N=352	Nashik N=349	Madurai N=172	Amritsar N=178	Total N=1051
Look	3.7	4.3	3.8	3.3	3.8
Speech	3.6	3.4	3.3	3.1	3.4
Overall adjustment in peer group	4.6	3.4	3.8	3.0	4.1

Overall satisfaction levels of the parents and family of the cleft lip/palate patient is very high across all the districts. On an average, looks after surgery got a rating of 3.8, speech got a rating of 3.4 and overall adjustment got a 4.1 score.

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<sup>9</sup> Only 3&5 respondents

A parent says:

*“When my first son was born with this congenital disease, I was afraid for his survival but later someone told me about the free surgeries provided by Smile Train all over India. Recently, my wife gave birth to a baby boy who is again born with a cleft lip and palate. This time though, I am not at all worried as Smile Train is here to help people like us”*

## FUTURE CONCERNS

**Table 8.12: Future concerns**

<b>Future concerns</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
<b>Patient's concern</b>					
Ability to get an education	4.1	4.0	3.7	2.4	3.7
Possibility of finding a job	3.6	3.4	3.2	2.4	3.3
Marriage Prospects	3.4	3.4	3.4	2.2	3.2
Having children with similar clefts	4.2	2.7	3.0	2.4	3.8
<b>Parent's/Family's concern</b>					
Ability to get an education	4.1	4.1	3.9	2.5	3.8
Possibility of finding a job	3.6	3.5	3.3	2.3	3.3
Marriage Prospects	3.5	3.4	3.1	2.2	3.2
Having children with similar clefts	4.2	2.5	2.9	2.5	3.6

This segment captures the future concerns of the patients and their family members that can affect the life of people born with cleft lip/palate. In order to gauge their perception about such aspects, respondents were asked to rate issues such as ability to get education, finding job and marriage on a scale of 1-5 with 1 as ‘have no concerns’ and 5 as ‘extremely concerned’. Data reveals that when a person is born with cleft lip/palate his/her parents are surrounded by various worries about the future lives of their children. High concern over having children with clefts is shown by patients with cleft lip/palate. Analysis of the data shows that across all the districts people are apprehensive about the chances of propagation of this defect in their offspring. Respondents from all the districts gave highest ranking (an average of 3.8) to their concern



over having children with clefts except respondents from Nashik who gave highest ranking to concern over ability to get education. Problem related to the ability of getting education for cleft lip/palate patients is the next big issue in the mind of the patients. The possibility of finding jobs is the third most significant issue for the patients in all the districts except for the patients of Madurai, for them finding a match for marriage is more difficult. For parents/families the most difficult challenge in front of their children with this defect is to get education.

One family member is hopeful that the work will carry on:

*“I want my son to be a surgeon so that he can be a part of Smile Train’s noble endeavour”*

Across all the studies districts parents indicate education as the prime concern (an average of 3.4). Respondents in almost all the districts identify the possibility of finding jobs as the next serious issue except for respondents of Jaipur, for them having children with similar defect is threatening.

## PRESENT STATUS OF PATIENTS

**Table 8.13: Present status of persons with cleft lip and/or palate post-surgery**

<b>Present status</b>	<b>Jaipur N=352</b>	<b>Nashik N=349</b>	<b>Madurai N=172</b>	<b>Amritsar N=178</b>	<b>Total N=1051</b>
<b>Education level:</b>					
Attending School	0.0	71.6	0.0	0.0	24.0
Pre primary	0.0	15.3	0.0	0.0	5.1
SSC	0.0	0.0	0.3	0.0	0.1
HSC	0.0	10.2	0.0	0.0	3.4
Graduation	0.0	2.8	4.9	0.0	2.6
Technical	0.0	0.0	2.3	0.0	0.8
NA	0.0	0.0	2.0	0.0	0.7
No answer	100.0	0.0	90.5	100.0	63.4
<b>Occupational status:</b>					
Farmer	0.0	0.9	0.0	0.0	0.3
Daily Wages	0.0	5.4	0.0	0.0	1.8
Skilled Worker	0.0	1.1	0.0	0.0	0.4
Salaried	0.0	2.0	0.0	0.0	0.7
Business	0.0	2.0	0.0	0.0	0.7
No answer	100.0	88.6	100.0	100.0	96.2

An attempt was made to understand the educational and economic impact of the Smile Train intervention. A majority of the respondents across districts did not reveal their present status with regard to education and/or occupational status. However, little less than a quarter (24.0%) of the respondents are presently attending school.

A respondent reports:

*“Earlier my son used to ignore people because he did not have the confidence, but now he meets people and mingles around with them. Smile Train has given an actual smile to my boy”*

A majority (71.6%) of the respondents from Nashik are attending school. With regard to occupational status, most respondents did not answer. However, few (5.4% and 2.0% each) of the respondents in Nashik report working as daily wage workers and as salaried or business workers respectively.

# Chapter 9

## Field Experiences

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### **INTERACTION WITH DOCTORS**

#### **Doctor's Feedback**

The process of developing appropriate responses to the medical and social problems faced by persons with cleft lips and/or palates is incomplete without a feedback from one of the most important stakeholders, the Doctors/surgeons.

The present chapter is devoted to cover interactions our field investigators had with the doctors responsible for performing corrective surgeries for cleft lip/palate patients. During in-person interviews, we engaged these doctors to gauge their opinion on various aspects of the issue such as socio-economic living conditions of the patients, general perception in the society towards cleft lip/palate cases, parental approach etc, nature of physical and psychological problems faced by persons with cleft lip/palate, their feedback on Smile Train's approach etc.

Our approach was to elicit qualitative feedback and no quantifiable questionnaire was shared with the doctors.

### **IMPACT OF ECONOMIC CONDITION ON OCCURRENCE CLEFT LIP AND/OR PALATE CASES**

The common belief is that occurrence of cleft lip and/of palate is confined to lower socio-economic and rural section of the society. Against this common belief, the consensus that emerged through the interviews is that all the doctors more or less agreed that the significant number of patients come from lower economic strata of the society or rural areas.

However, the reasoning given by the doctors varied. While one doctor at a hospital attributed higher cases in lower economic section and rural area to higher proportion of these sections in overall population, another believes that Smile Train Survey may throw higher numbers in poor/rural sections because the economically rich families or urban families take up immediate corrective actions in such cases and thus remain out of Smile Train net. While one doctor agreed that most his patients belonged to economically weaker section, he took no position on

the reasons thereof, a government hospital doctor was emphatic in his opinion that cases dealt by his hospital are pre-dominantly from economically weaker section.

### **AWARENESS AMONG PATIENTS – CHANGE IN PERCEPTION**

All the doctors shared similar experiences in regards to the misconceptions regarding cleft lip in the society with common culprits being effect of eclipse, reincarnations, mother's bad deeds, and in some cases (bilateral cleft lips) the personification of God. Absence of scientific reasoning and lack of information regarding corrective measures often result in delay in corrective surgeries and severely stunt the physical and social growth of the individual. Almost all the doctors agreed that the level of awareness has gone up in past one decade and this has helped in removing a various superstitions and has made corrective surgeries far more acceptable.

A medical practitioner observed that, "today the level of awareness about the cleft lips and Palate defects is very high in comparison to what it was ten years ago when Smile Train started working in India. Earlier, slew of superstitions such as effect of eclipse, reincarnation of ancestors etc. were attached to this congenital defect. In the past, due to such prevalent beliefs, people were reluctant to approach hospitals for corrective surgeries. However, now it is very rare to find such reluctance among people."

On the other hand, a local doctor was of the opinion that in rural areas, the level of unawareness is still very high and the people still tend to ascribe cleft lip to wrath of god, stars etc. To cover this information deficit, his hospital is running awareness campaigns which are funded by Smile Train. He further stressed that there is a need to take parents/family into complete confidence to ensure proper expectation management as many families actually believe that the surgery would resolve all the appearance and functional problems and often are not prepared for uneven teeth, nasal speech and distortion of nose structures.

### **PROBLEMS FACED BY THE PATIENTS**

While the doctors agreed that increased awareness has helped the patients by removing superstitions surrounding the cleft lips, they continue to face other problems which doctors classified into –

1. Functional,
2. Appearance and social stigma attached to it and;
3. Psychological

A doctor from a leading hospital stressed upon two fundamental functional problems: inability to eat and speak properly. According to him once the palate development stage has passed, the corrective surgeries are sufficient for speech development and therefore early intervention is essential.

While the doctors didn't stress too much on appearance related issues as they can be corrected at any age, they did stress on the stigma that emanates from abnormal looks combined with abnormal speech. According to a few doctors, persons having cleft lips/palate often face public mocking due to their nasal and broken speech along with their abnormal looks. The government doctor further argued that the difficulty in speech inhibits normal interaction with the society which leaves such persons with apparent disadvantage in social engagements. This often results in isolation, introvert outlook and other psychological problems.

A district doctor shared a very interesting case which reflects the social stigma people with cleft lips face. Once, a sixty year old lady approached him for the corrective surgery. When asked for reasons why she wants to have the surgery at such an old age, she responded, "I want to remove the eternal taunt from my life because whenever I do anything wrong my husband curse me by saying that I have a cleft lip. He stressed that there is need to follow up cleft lip/palate surgeries with orthodontic treatment and speech therapy wherever required. However, such facilities are often not available which leaves the patients with lack of proper speech even after cleft lip surgeries.

### **FEEDBACK ON SMILE TRAIN**

The general feedback was very positive from doctors regarding functioning of Smile Train. A local doctor advocated the use of Smile Train model for interventions in other medical problems too. Commenting on a recent incident in a sterilisation camp in Chattisgarh, he said that Smile Train model proves that there is no need for camp models and that this model provide three key ingredients for the success of State or NGO intervention, namely:

- Continuity of the surgery
- Proper as well as regular post-surgery follow-ups
- Removal of hindrance due to alien environment because when a surgeon perform operation in a camp, he faced so many difficulties such as lack of proper sterilisation, quality equipment etc.

According to the government hospital doctor, in many cases there is a need for secondary surgery. Therefore, there is need for Smile Train to provide funds for such surgeries too. A private doctor, on the other hand, observed that there is need to surgeons involved in Smile Train problem to improve their skills as improper surgeries are leaving many patients with nasal speech which should not be the case if the surgery is carried out properly. He suggested that the focus should remain quality instead of quantity and practices like appointment of PROs on commission basis should be looked into.

## **FIELD OBSERVATIONS**

Along with data collection work, the field investigators met with local Zilla Parishad officials, local doctors, anganwadi teachers, respondents and their families and other community members and gathered information about their perceptions about patients with cleft lips and palates. Interactions with respondents revealed that a large proportion of the population still believes that cleft lips and palates are either a result of expecting mothers cutting vegetables during an eclipse or a result of God's will, both of which cannot be corrected or reversed. Few of the respondents were also found to lack awareness or knowledge about the exact cause of cleft lips and palates. Other commonly held perceptions about causes of such disabilities were seen to be improper pre-natal maternal care, heredity and some fault in the parents' stars/astrology.

Interactions with respondents revealed that some of the patients were operated upon in their childhood itself, due to which, their everyday life was observed to be progressing well. Those patients who were operated while they were attending school were observed to be doing better in their school life after their surgery. While earlier those with cleft lips and palates were made fun of and were ridiculed, especially among school going children, after surgery, these patients were found to be more confident in their outlook and in their general interactions with people. They reported that the surgery has made a big difference to their everyday life. It was also

observed that, among school-going patients who were teased, few of them refused to go to school as well. However, these patients were found to have confided in the doctors, who were reported to play a major role in boosting their confidence prior to the surgery. In addition, information about Smile Train and its work in correction of cleft lips and palates was displayed at the PHC. In addition, doctors at the PHC also inform visitors about Smile Train interventions in this area.

While most people in the study districts were found to be aware about Smile Train's activities, many people residing in the villages were seen to be unaware about the same. However, with the use of media such as newspapers, posters and pamphlets, this was also seen to be dealt with. With regard to the marriage patterns among the patients, it was largely observed that those patients found it difficult to find partners. However, after the correctional surgery was performed, finding suitable partners was reported to be relatively easier.

Overall, the role of the Smile Train and doctors associated with its work among the general study population was observed to be highly valued. The respondents and their families alike were seen to be highly appreciative of the "social work" the Smile Train organisation had done in their respective village. Conducting correctional surgeries, free of cost, was stated as an important and much-needed service, by the respondents. It was largely found that while respondents may not remember the names of the hospitals where the patient underwent correctional surgery, Smile Train was very well recollected by all of them. In addition, the respondents were seen to be most appreciative of the doctors associated of the Smile Train project.

### **PERCEPTION AMONG FAMILY MEMBERS**

Parents and family members of the cleft lips and palates patients were observed to be generally happy about the outcome of the surgery. However, interactions with some of them revealed that while parents reported a visible change in the appearance of the patients, their speech did not seem to be improved significantly, as they had expected. Especially with reference to patients with palates, a few family members informed that the patients' speech had still not improved, even after the surgery and they expressed concerns over the patients' ease in their future life. A few parents reported that they were unhappy as in the case of some children, the stitches opened up. However, this issue was corrected in subsequent surgeries.

With regard to the marriage of patients, family members reported that after the surgery, looking for suitors for their children had become easier. In addition, other family members informed that after correction, their children got married and were leading comfortable lives.

Parents were also found to be very supportive of the patients and were observed to have played a major role in building their confidence in everyday life. Another aspect mentioned by parents/family members was that post-surgery follow-ups needed to be laid emphasis on, with respect to feeding/food intake patterns and such information.

Overall, people were found to be highly satisfied with the intervention by Smile Train. It was largely found that more such interventions were sought, especially given the impact the correctional surgeries had on the patients' education, marriage and occupational status. Smile Train was largely felt to be perceived as a large step in incorporating people born with cleft lips and palates in the mainstream society.



## Chapter 10

### Summary and Recommendations

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In India, there is one case of cleft lip and/or palates in every 5000 (approximate) live births. While aspects such as pre-natal complications, environment and other medical complications are cited as reasons for the occurrence of such defects, there is still no scientific proof of the exact cause of this disability. The present study attempted to provide a comparative analysis of the profile, socio-economic status, perception and efforts to address the correction of the disability among the persons with cleft lips and/or palates and the relevant responses from their family members. It also covered some new aspects such as the awareness and feelings of the respondents before, during and after the surgical process as well their present educational and occupational status. The study also examined the incidence rate of cleft lips and/or palates across the study districts and in India as a whole and compared the findings from the same to the earlier conducted study. The study expected to provide strategies for more effective and timely interventions in its regard.

Four states, namely Maharashtra, Rajasthan, Punjab and Tamil Nadu were selected for the present study. These states are not only geographically representative for India, but also they vary in levels of development. Field staff utilised various sources of information like multipurpose health workers (both male and female), aganwadi teachers, panchayat officials, traditional birth attendants (*dais*), local NGO representatives and cleft cases themselves for the identification of cleft cases in the study areas. Altogether 1051 cleft cases were reported in the study districts of Nashik (349), Jaipur (352), Madurai (172) and Amritsar (178). An interview schedule covering major issues namely identification information, background information of a person with cleft lip and/ or palate, their perceptions of the disability and their efforts to correct the disability was administered to the cleft cases and necessary information from them was obtained.

#### STUDY FINDINGS

##### Profile of Persons

Sex-wise analysis of the persons with cleft lips and/or palates reveals that two thirds (63.1%) are males and about one third (36.4%) are females as seen in all the study areas (Jaipur, Madurai and Amritsar) with the exception of Nashik, where more than half (59.3%) males and 40.7 per

cent females had cleft lips and or/palates. As per the age distribution among the respondents, a majority (37.1%) of them were below 5 years of age, followed by less than a quarter (21.6%) of them who were more than 20 years of age. District-wise data shows little variation with similar proportions of respondents in Jaipur (45.7%), Nashik (38.7%), Madurai (30.2%) and Amritsar (23.6%) below 5 years of age. Variations were seen among the respondents with cleft lips and/or palates above 20 years of age in the study areas of Madurai (37.2%) and Amritsar (34.8%) and those from Nashik (15.2%) and Jaipur (13.6%). Across all districts, data on marital status shows that nearly three-fourth (74.0%) of the respondents are single with few of them being married and widowed or divorced. District-wise data reveals that a majority (91.8%) of the respondents in Jaipur are single, followed by 89.4 per cent of them from Nashik, who are also married. Less than half (42.6%) of the respondents from Madurai are single while 38.2 per cent of them from Amritsar are single. Overall, a majority of the patients with cleft lip and/or palates are illiterate (23.9%), while an almost equal proportion (23.0%) of the respondents is in the secondary level of their education (that is, Class V-X). About 18.3 per cent of the total respondents are studying in the primary level (Class I-IV) and 13.3 per cent of them are illiterate. One-tenth (10.2%) of the respondents are in college (Class XI onwards).

District-wise data shows that illiterate respondents are found in a higher proportion in Jaipur, with almost a quarter (24.4%) of them reporting the same. Few (18.0%) respondents in Amritsar are illiterate, while 9.9 per cent of them, followed by 1.4 per cent of them in Madurai and Nashik respectively, who are illiterate. Similar proportions of respondents across all districts are seen as not yet attending school viz., 28.1 per cent respondents from Nashik, 23.8 per cent and 23.6 per cent in Madurai and Amritsar and 19.9 per cent respondents in Jaipur.

Overall, a majority of the patients with cleft lip and/or palates are illiterate (23.9%), while an almost equal proportion (23.0%) of the respondents is in the secondary level of their education (that is, Class V-X). About 18.3 per cent of the total respondents are studying in the primary level (Class I-IV) and 13.3 per cent of them are illiterate. One-tenth (10.2%) of the respondents are in college (Class XI onwards).

District-wise data shows that illiterate respondents are found in a higher proportion in Jaipur, with almost a quarter (24.4%) of them reporting the same. Few (18.0%) respondents in Amritsar are illiterate, while 9.9 per cent of them, followed by 1.4 per cent of them in Madurai and Nashik respectively, who are illiterate. Similar proportions of respondents across all

districts are seen as not yet attending school viz., 28.1 per cent respondents from Nashik, 23.8 per cent and 23.6 per cent in Madurai and Amritsar and 19.9 per cent respondents in Jaipur. Data on the occupational status of the persons with cleft lip and/or palates reveals that 42.8 per cent of them are students, followed by 30.3 per cent of them who are not yet going to school. Few (5.6%) of them are daily wage earners.

District-wise data shows some variations with regard to the occupational status of the respondents. Among those who are students, a little over half (51.6%) are from Nashik, followed by 46.0 per cent who are from Jaipur

. Less than half (41.2%) of the respondents who are not yet going to school, live in Jaipur. More than a quarter (28.4%) of the respondents who are not yet going to school are from Nashik, followed closely by 25.6 per cent of them who are from Madurai.

### **Family Background of Persons with Cleft Lips and/or Palates**

With regard to the type of family, more than half (57.4%) of the respondents live in joint families

A few variations were seen among districts with a majority (82.4%) of the respondents from Jaipur who live in joint families, followed by 66.5 per cent respondents from Madurai who live in nuclear families.

More than half (59.0%) of the respondents from Amritsar are in nuclear families while 52.1 per cent of them from Nashik live in joint families and 47.3 per cent of them from the same district live in nuclear families.

Overall, most (36.3%) of the households have four to five members in the household.

Data from the districts show that a majority (62.2%) of the respondents with 4-5 family members are in Madurai, while less than half (49.4%) of them with the same number of family members live in Amritsar. With regard to 10-plus sized households, Jaipur ranks first (32.3%) among the districts.

With regard to data on the family income of the respondents, less than half (46.3%) of them did not answer, followed by a quarter (25.6%) of them whose family income is less than Rs.5000. Slightly more than half (51.7%) of the respondents from Madurai have a family income in the Rs.5001-10000 income bracket, while 16.6 per cent respondents from Nashik

and 12.9 per cent of them from Amritsar are in the same income range. The mean family income is Rs.12, 362 in Nashik, Rs.11,631 in Jaipur, Rs.7, 237 in Madurai and Rs.6, 146 in Amritsar. A majority (92.6%) of the respondents in general do not have family members with similar disabilities.

### **Background of the Mothers**

Less than half (44.3%) of the respondents report non-consanguineous marriages for their mothers. The mean number of conceptions are 2.7 in general and are 2.9 for Amritsar, 2.8 for Nashik, 2.7 for Jaipur and 2.5 for Madurai. Half (50.0%) of the respondents report other pre-natal complications, while 42.6 per cent of the mothers had no pre-natal complications. Few (3.4%, 1.7% and 1.6%) of the respondents report fever, anaemia and ill health as pre natal complications.

### **Perceived Causes, Earlier Efforts and Readiness for its Corrections**

Less than half (44.5%) of the total respondents perceive cleft lips and/or palates to be a result of God's will. Less than a quarter (23.1%) of them state that the disability is a result of an eclipse. District-wise variations are seen in the same regard with Jaipur showing the highest (84.7%) proportion of respondents who state God's will as a cause of the disability while Amritsar and Nashik show similar proportions (47.2% and 47.0% respectively) of respondents who report God's will and eclipses respectively as perceived causes of the disability. About 33.7 per cent respondents from Amritsar perceive that the disability is caused by an eclipse, followed by 28.7 per cent of the respondents from Madurai who perceive bad luck as a cause of the disability. With regard to the earlier efforts made to correct the disability, three-fourth (75.5%) of the respondents overall had operations. Districts showed no variations in this regard with majority of the respondents across all of them having operations. In general, 56.0 per cent respondents show readiness to correct the disability if provided with the opportunity to do so. A qualitative analysis reveals that most respondents became aware about cleft corrections through Smile Train camps, advertisements in newspapers or at the local Primary Health Centre (PHC), doctors, family members or other community members who had corrective surgeries or corrected surgeries.

With regard to the perceptions of the respondents as to who should provide care to such disabled persons, more than half (54.03%) of them believe it should be mothers, followed by 50.4 per cent of them say it should be fathers while more than a quarter (30.5%) of the

respondents say it should be the government through special schemes and support. It is significant to note that a rise is seen among those who already had corrective surgery. Earlier, this category consisted of only a quarter respondents, however, in the present study, almost three-fourth (75.5%) respondents report to already being operated.

### **Incidence of Cleft Lip and/or Palate**

Incidence rates for the study districts and the country as a whole are also worked out.

<b>District</b>	<b>Incidence Rate of Cleft Cases</b>
Jaipur	One in 5882 live births
Nashik	One in 3448 live births
Madurai	One in 4545 live births
Amritsar	One in 3030 live births
<b>Total</b>	<b>One in 4762 live births</b>
<b>India</b>	<b>One in 4952 live births</b>

### **Recommendations**

The present study on providing a comparative analysis of persons with cleft lips and/or palates will help providing more timely and effective intervention in the correction of cleft lips and/or palates. Some of the recommendations that have emerged from both the studies are:

1. Given the vast number of cases still being reported in the country, and with the recent data on the incidence rate, streamlining processes in terms of recognising patients, providing timely medical assistance and providing post-surgery care may be looked at
2. Programmes need to be devised to sensitise all those stakeholders that may have a direct or indirect impact on the lives/livelihood of persons with cleft lips and/or palates. In addition, special sensitisation programmes may be considered for teachers, medical professionals as well as representatives of non-governmental organisations to help improve access to quality facilities and to integrate such person into the mainstream society. This is of crucial importance especially with the inclusion of the Right to Education in the Fundamental Rights under the Constitution
3. Counselling Centres may be set up to consult and counsel the patients themselves as cleft lips and/or palates have some severe psychological impacts on the patients

4. The role of non-governmental organisations (NGOs) and community based organisations (CBOs) in sensitising community members towards inclusion of such persons may also be explored
5. CBOs engaged in work with persons cleft lips and/or palates may include, in their projects and programmes, the family members or care givers of such persons to facilitate easy access to doctors and institutions working in the same field
6. A major area of possible intervention that may be looked at is the Corporate Social Responsibility (CSR) departments of various public and private undertakings. Projects such as 'Adopt-A-District' may be introduced (on a pilot basis), wherein companies may take the responsibility of making one district in their area of operation Cleft-free
7. The media must be incentivised to undertake awareness campaigns about the disability as awareness about the occurrences of cleft lips and/or palates is seen to be poor. In addition, success stories of past corrected cases, who are performing well on economic and educational indicators, may be highlighted to encourage more people to come forward and get the disability corrected
8. Efforts should be made through the National Health Mission, recognise that in all public institutions, dentists and related medical professionals have to be trained to identify and assist in cleft lip and/or palate cases

## *Appendix*

TATA INSTITUTE OF SOCIAL SCIENCES

DEONAR, MUMBAI – 400 088

Research Study On “Children born with Cleft Lip and / Palate in India”

### INTERVIEW SCHEDULE

Schedule No.: .....

State : \_\_\_\_\_

#### I. Identification:

**1. Name and address of the person with Cleft Lip and / Palate:**

*Name:*

*Address:*

*District: Nashik / Madurai / Jaipur/Amritsar*

*State: Maharashtra / Tamil Nadu / Rajasthan/ Punjab*

**2. Respondent (if other than the person with Cleft Lip and / Palate):**

*Name:*

*Address:*

*District: Nashik / Madurai / Jaipur/Amritsar*

*State: Maharashtra / Tamil Nadu / Rajasthan/ Punjab*

#### *Relationship:*

Mother

Father

Brother

Sister

Uncle

Others (Specify):

#### **3. Type of Cleft Lip and / Palate:**

At Birth :

Cleft lip (i) No

nilateral

Bilateral

(iv) Other

Cleft Palate

(i) No

(ii) Partial

(iii) Complete

Both

(i) Cleft Lip Unilateral and Palate

(ii) Cleft Lip Bilateral and Palate

II. Background Information of the person with Cleft Lip and / Palate:	Socio-Economic Status of the Respondent (if the person is other than that with Cleft Lip and / Palate):
<p><b>1. Age :</b> .....Years.....Months</p> <p><b>2. Sex:</b></p> <p style="padding-left: 100px;">Male.....1</p> <p style="padding-left: 100px;">Female.....2</p> <p><b>3. Religion:</b></p> <p>Hindu.....1 Sikh.....4</p> <p>Muslim.....2 Buddhist.....5</p> <p>Christian.....3 Jain.....6</p> <p>No Religion.....7</p> <p>Others (Specify).....8</p> <p style="padding-left: 40px;"><b>Caste:</b> .....</p> <p><b>4. Type of Family:</b></p> <p style="padding-left: 40px;">Nuclear.....1</p> <p style="padding-left: 40px;">Joint.....2</p> <p style="padding-left: 40px;">Single Person H.H. ....3</p> <p style="padding-left: 40px;">Extended Family.....4</p> <p><b>5. Education:</b></p> <p>Illiterate .....1</p> <p>Not yet going to school.....2</p> <p>Lower K.G.....3</p> <p>Primary (1 to 4 Std.) .....4</p> <p>Secondary (5 to 10 Std.) .....5</p> <p>Collegiate (11 Std. onwards) .....6</p> <p>Vocational Training .....7</p> <p>Technical .....8</p> <p>Others (Specify).....9</p> <p><b>6. Occupation:</b></p> <p>Student.....1</p> <p>Not yet going to school.....2</p> <p>Hawker / Vendor.....3</p> <p>Daily wage earner .....4</p> <p>Shopkeeper.....5</p> <p>Regular worker in industry/workshop .....6</p> <p>Regular worker in office.....7</p> <p>Auto driver/ Bus conductor/Bus driver... 8</p> <p>Domestic Servant.....9</p> <p>Presently Unemployed.....10</p>	<p><b>1. Age :</b> .....Years.....Months</p> <p><b>2. Sex:</b></p> <p style="padding-left: 100px;">Male.....1</p> <p style="padding-left: 100px;">Female.....2</p> <p><b>3. Religion:</b></p> <p>Hindu.....1 Sikh.....4</p> <p>Muslim.....2 Buddhist.....5</p> <p>Christian.....3 Jain.....6</p> <p>No Religion.....7</p> <p>Others (Specify).....8</p> <p style="padding-left: 40px;"><b>Caste:</b> .....</p> <p><b>4. Type of Family:</b></p> <p style="padding-left: 40px;">Nuclear.....1</p> <p style="padding-left: 40px;">Joint.....2</p> <p style="padding-left: 40px;">Single Person H.H. ....3</p> <p style="padding-left: 40px;">Extended Family.....4</p> <p><b>5. Education:</b></p> <p>Illiterate .....1</p> <p>Lower K.G.....2</p> <p>Primary (1 to 4 Std.) .....3</p> <p>Secondary (5 to 10 Std.) .....4</p> <p>Collegiate (11 Std. onwards) .....5</p> <p>Vocational Training .....6</p> <p>Technical .....7</p> <p>Others (Specify).....8</p> <p><b>6. Occupation:</b></p> <p>Student.....1</p> <p>Hawker / Vendor.....2</p> <p>Daily wage earner .....3</p> <p>Shopkeeper.....4</p> <p>Regular worker in industry/workshop .....5</p> <p>Regular worker in office.....6</p> <p>Auto driver/ Bus conductor / Bus driver.....7</p> <p>Domestic Servant.....8</p> <p>Presently Unemployed.....9</p>



<p>Agriculturist.....11 Housewife.....12 Any other (Specify).....13</p>	<p>Agriculturist.....10 Housewife.....11 Any other (Specify).....12</p>
<p><b>7. Income:</b> a. CLP's monthly income Rs. • Family Income per month Rs. • No Income</p>	<p><b>7. Income:</b> a. Respondent's monthly income Rs. b. Family Income per month Rs. c. No Income</p>
<p><b>8. Type of House:</b> Semi Pucca.....1 Pucca .....2 Tenant in Chawl .....3 Hut.....4 Kachcha.....5 Others (Specify) .....6</p>	<p><b>8. Type of House:</b> Semi Pucca.....1 Pucca .....2 Tenant in Chawl .....3 Hut.....4 Kachcha.....5 Others (Specify) .....6</p>
<p><b>9. Migration Status:</b> Non-Migrant.....1 Migrant.....2 If Migrant, Place of Origin: District..... State.....</p>	<p><b>9. Migration Status:</b> Non-Migrant.....1 Migrant.....2 If Migrant, Place of Origin: District..... State.....</p>
<p><b>10. Marital Status:</b> Single.....1 Married.....2 Widow.....3 Divorcee.....4 Widower.....5</p>	<p><b>10. Marital Status:</b> Single.....1 Married.....2 Widow.....3 Divorcee.....4 Widower.....5</p>
<p><b>11. Type of Marriage:</b> Consanguineous .....1 Non-Consanguineous.....2</p>	<p><b>11. Type of Marriage (of the parents of the person with Cleft Lip &amp; / Palate):</b> Consanguineous .....1 Non-Consanguineous.....2</p>
<p><b>12. How many conceptions did you / your spouse have altogether?</b></p>	<p><b>12. How many conceptions did she have altogether?</b></p>

**13. Details about outcome of conceptions:**

Sr. No.	Age at each conception (in years)	Place of birth: Home/Hospital	Outcome of conception (IA/SA/ SB/ BD /LIV)	Sex of the child	Any disability (Specify)	If dead		
						Age at Death	Cause of death	Place of death: Home/Hospital
1.								
2.								
3.								
4.								
5.								
6.								
7.								
8.								
9.								
10.								

\* (IA: Induced Abortion, SA: Spontaneous Abortion, SB: Still Birth, BD: Born but died, LIV: Living)

**14. Did you experience any complications/problems during pre-natal period (related to the child with cleft lip/palate)?**

- Anemic .....1
- Fever.....2
- Accident.....3
- Intake of drugs (Specify the details).....4
- Ill-health (Specify the details).....5
- Others (Specify).....6

**15. (a) Total members in the household:**  
(including the respondent)

--	--

**(b) Do any of your family member has similar disability?**

- Yes.....1
- No.....2

**If yes, Details:**

Sex: Male  Female

Relationship:

Parents: Mother  Both

Siblings: Brother  Both

Cousin

Others (Specify).....

**Type of disability:**

• *Cleft Lip alone:*

i) Unilateral

(ii) Bilateral

*2. Cleft Palate alone:*

(i) Partial

(ii) Complete

*3. Cleft Lip and / Palate:*

(i) Cleft Lip Unilateral and Palate

(ii) Cleft Lip Bilateral and Palate

**III. Perceptions about Disability:**

*1. According to you what are the causes for this disability?*

(Respondent can name more than one. Circle all that he/she mentions)

- Physical / Physiological.....1
- Heredity.....2
- Bad-Luck.....3
- Negligence by Families.....4
- Past – birth karma.....5
- Faulty pre-natal care.....6
- Consanguineous Marriage.....7
- Superstitious beliefs (specify).....8
- Eclipse.....9
- God's will.....10
- Some medication.....11
- Substance Abuse(Tobacco, Alcohol).....12
- There is no reason just an accident.....13
- No idea/ Don't know.....14
- Others (Specify).....15

**2. Do you think that persons with this disability are like any other member of the community?**

Yes.....1

No.....2

Uncertain.....3

If no, how?

**3. Do you agree that person with this disability needs special care?**

Yes.....1

No.....2

Uncertain.....3

**What Special Care?**

**4. Who should provide such care?**

(Respondent can name more than one. Circle all that he/she mentions)

Father.....1

Mother.....2

Siblings.....3

Neighbours.....4

Community.....5

NGO (Voluntary Organisation).....6

Government.....7

Not known.....8

Others (Specify).....9

**5. Do you know any other disabled person (including Cleft Lip and / Palate cases) living?**

in your neighbourhood.....1

in your lane.....2

in your community.....3

in your workplace.....4

anywhere else (specify).....5

**If yes, give their details (including their addresses):**

**6. According to you, what are the causes for their occurrence? How can they be cured? What are the preventive measures usually done for their non-occurrence?**

Sl. No.	Common Disability	Causes	Curative Measures	Preventive Measures
1.				
2.				
3.				
4.				
5.				
6.				

**IV. Efforts to correct the disability:**

**1. For any illness whom you and your family member first contact for treatment?**

Private practitioner (Specify)

Govt. Doctor (Specify)

Others (specify).....

**2. Do you know that Cleft Lip and / Palate can be corrected?**

Yes  No

If yes, how?

**3. According to the patient/mother/family, how did they learn about treatment possibility?**

- Word of mouth, From the similarly affected patients/parents.....1
- Newspaper Advt.....2
- Social Worker.....3
- Field Camp by Smile Train Partner.....4
- Muskan Utsav.....5
- From a doctor.....6
- Outreach staff of Smile Train Partner.7
- Other.....8

**4. What are the earlier efforts made by you to correct the disability?**

No efforts made

Uncertain

Efforts made include the following

*Please specify (i) The earlier efforts:*

(ii) Outcome: Corrected partially  Corrected, but failed

Correction differed for reasons like \_\_\_\_\_

**5. Details about earlier surgeries**

No. of surgeries	0	1	2	3	4
For what purpose					
Age at the time of surgery					
Location					

**6. Awareness and Feelings before surgery**

Patient's awareness and feelings :

Too young; was not aware

Didn't matter;was no problem

Felt mildly excluded

Felt totally excluded

Others(specify)

Mother/family's awareness and feelings:

Had full family/ peer support

Looked down upon

Taunted but accepted

Abandoned and excluded

Others(specify)

**7. Information about the surgery**

**7a. How far did the patient/family had to travel for treatment? \_\_\_\_\_ km**

**7b. Was the patient accepted for the treatment and admitted for surgery at the first visit?**

**Yes                      No**

**If No, Specify:**

Patient medically not fit                     

Other patient waiting                     

Others (specify)                     

**7c. How long did the patient have to wait for surgery after first visit?**

Less than 15 days                     

16-30 days                     

31-45 days                     

more than 45 days                     

**7d. Did the patient/parents receive any counselling at the first visit, e.g. on how to feed the child?**

**No              Yes**

**If Yes, Specify:**

**7e. At the time of surgery,**

**How many days did the patient have to stay in the hospital? \_\_\_\_\_**

**Were any travel expenses reimbursed, or was any financial help received? Yes No**

**If Yes, how much? \_\_\_\_\_**

**For what purpose received:**

**8. Information about Post Surgery**

**Use a 1-5 scale with 1 as 'Highly Dissatisfied' and 5 as 'Completely Satisfied' regarding following aspects**

Patient's satisfaction:

Look                     

Speech                     

Overall adjustment in peer group                     

Parents/family's satisfaction:

Look                     

Speech                     

Overall adjustment in peer group                     

**9. What is the patient doing now?**

**9a At School:**

**Which Class?**

**Performance Level (specify)**

**9b. Working:**

**Where?**

**As What?**

**Approximate earning per month (in Rs.)**

**Not doing anything**

**Other changes (specify):**

**10. Future concerns**

*Use a 1-5 scale with 1 as 'Have no concern' and 5 as 'Extremely concerned' regarding following aspects*

Patient's Concern :

Ability to get an education	<input type="checkbox"/>
Possibility of finding a job	<input type="checkbox"/>
Marriage prospects	<input type="checkbox"/>
Having children with similar clefts	<input type="checkbox"/>
Others(specify)	<input type="checkbox"/>

Parents/Family's Concern :

Ability to get an education	<input type="checkbox"/>
Possibility of finding a job	<input type="checkbox"/>
Marriage prospects	<input type="checkbox"/>
Having children with similar clefts	<input type="checkbox"/>
Others(specify)	<input type="checkbox"/>

**11. If opportunity is provided for its correction, are you willing to undergo surgery?**

Yes

No

Uncertain

If no, specify the reason:

If yes, your preference in terms of :

(i) place:

(ii) logistics (specify):

(iii) help (specify):

**REMARKS:**