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# Cleft Lip and Palate in India: Determining the Socioeconomic Factors That Influence Quality of Life and Treatment Received, With a Focus in Rural Nainital District, Uttarakhand State

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CLEFT LIP AND PALATE IN INDIA: DETERMINING THE SOCIOECONOMIC FACTORS THAT  
INFLUENCE QUALITY OF LIFE AND TREATMENT RECEIVED, WITH A FOCUS IN RURAL  
NAINITAL DISTRICT, UTTARAKHAND STATE

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## **Table of Contents**

<b>Acknowledgements</b> .....	<b>3</b>
<b>Abbreviations</b> .....	<b>4</b>
<b>Abstract</b> .....	<b>5</b>
<b>Introduction</b> .....	<b>5</b>
What is a cleft?.....	5
Why focus on Nainital?.....	7
Project questions and goals.....	9
Field study methods.....	9
Brief statement of findings.....	10
<b>Cleft Statistics</b> .....	<b>11</b>
<b>Causes of Clefts</b> .....	<b>12</b>
<b>Challenges of Life with a Cleft and Factors that Perpetuate them</b> .....	<b>14</b>
Physical challenges.....	14
Social challenges.....	18
<b>Challenges Obtaining Treatment and Factors that Perpetuate them</b> .....	<b>26</b>
Awareness of and motivation to pursue care.....	27
Availability and accessibility of care.....	35
<b>Conclusions</b> .....	<b>42</b>
<b>Project Limitations</b> .....	<b>44</b>
<b>Recommendations for Further Study</b> .....	<b>46</b>
<b>Bibliography</b> .....	<b>48</b>
Primary Sources.....	48
Secondary Sources.....	49
<b>Appendix</b> .....	<b>54</b>
Sample Interview Questions for Cleft Patients/Guardians.....	54

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## **Abbreviations**

ASHA	Accredited Social Health Activist
BPL	Below Poverty Line
CL	Cleft Lip
CLP	Cleft Lip and Palate
CP	Cleft Palate
JSY	Janani Suraksha Yojana
NGO	Non-Governmental Organization
NRHM	National Rural Health Mission
RBSK	Rashtriya Bal Swasthya Karyakram
RSBY	Rashtriya Swasthya Bima Yojana
UK	Uttarakhand state

## **Abstract**

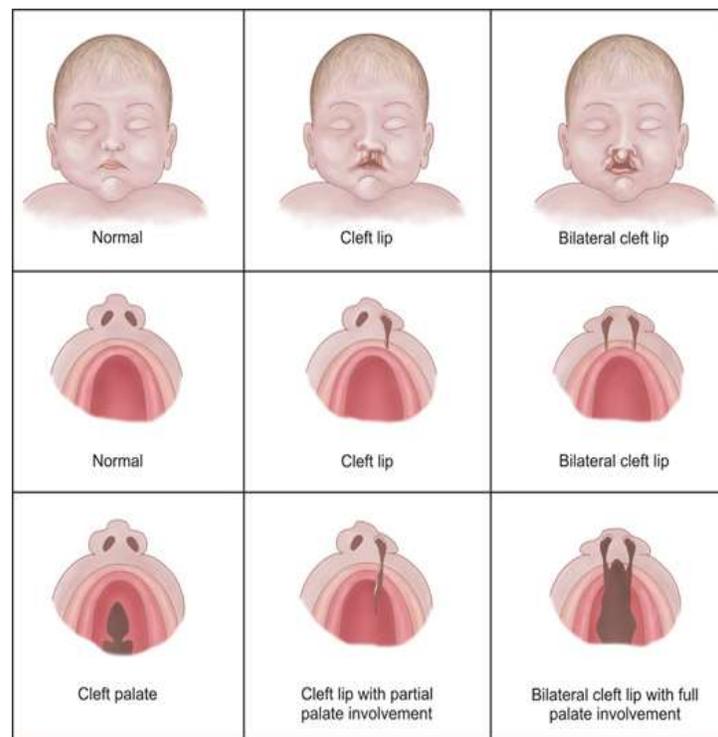
Cleft lip and cleft palate are birth defects that range in severity, and may cause serious physical and social challenges to those who are born with them. This project sought to determine the socioeconomic factors that influence the lives of people with cleft lip and or cleft palate in India, and the treatment, or lack thereof, which they receive. Specific focus was given to the rural and mountainous area of Nainital district in Uttarakhand state. This study was carried out with the assistance of the Aarohi organization located in the Satoli village in Nainital district. Interviews with one plastic surgeon who treats cleft, one nurse who works for an NGO-run hospital in rural Nainital, one adult cleft patient, and the guardians of five cleft children were conducted, and socioeconomic indicators were compared with treatment experiences and quality of life. The results of this fieldwork found that a wide range of factors, such as lack of health education and awareness of the cleft repair procedure, as well as the difficulties posed by isolated and hilly terrain and low income levels, had a negative impact on the lives and treatment outcomes of cleft patients in rural Nainital.

## **Introduction**

### **What is a cleft?**

The word “cleft” means a split or a fissure (Meyer-Marcotty, Gerdes, Reuther, Stellzig-Eisenhauer, Alpers, 2010). During normal fetal development, separate areas of the face grow individually and then join together in early gestation. Sometimes however, there is incomplete fusion of the upper lip and or the hard palate bone or the soft palate bone that form the roof of the mouth. This is a cleft. The cleft may be unilateral, occurring on one

side of the face, or bilateral, occurring on both the left and right sides. As seen in Figure 1, there may be a cleft in just the lip (CL), just the palate (CP), or both (CLP). As a result, there is a wide range in the severity of clefts and their resulting problems, as well as in the complexity of the treatment required to mend clefts. While clefts in the lip are more visible, clefts in the palate generally cause more physical challenges to the patient because of the hole between the roof of the mouth and the nasal cavity. If not properly cared for, clefts can lead to numerous health issues such as malnutrition and stunting, as well as speech, hearing, and nasal breathing difficulties. Furthermore, people with clefts are often subject to intense social stigma and discrimination.



*Figure 1. Various levels of clefts.*

Clefts sometimes occur as part of another syndrome. These clefts are referred to as syndromic clefts, whereas if the cleft is the only abnormality that the child is born with, it is termed a nonsyndromic cleft. Various studies have calculated a wide range of percentages for the amount of clefts that are syndromic. These numbers range from 3 percent up to 63 percent (Venkatesh, 2009). The differences in these findings may be attributable to genetic variations within the populations of study, as well as variations in how each study was conducted and how each researcher defined their terms. More than 400 syndromes have been identified as having genetic links with clefts. Some of the most common are Pierre Robin sequence, Van der Woude's syndrome, and Velocardiofacial syndrome (UC Davis, 2014). With the exception of one boy who has both a CP and Down syndrome, this paper will discuss nonsyndromic clefts and the issues that they present to children who are born otherwise normal.

### **Why focus on Nainital?**

As compared to many other parts of the world, being born with a cleft in India presents tougher physical and social challenges. Until recently, there has been a critical lack of treatment available to cleft patients in India, and if it was available, care has generally not been physically or economically accessible to the majority of Indians who need it. The Indian government is less able than the administrations of many other countries to make the full range of recommended cleft care services widely obtainable to its population. The Indian Supreme Court has ruled that the right to health is integral to the right to life that is guaranteed to the Indian people under article 21 of the Constitution (Prasanth, 2014). However, although India has the fourth largest GDP in the world, the country spent only 1.3 percent of its GDP on public health in 2012 (World Bank, Health expenditure, 2014). India

ranks 126<sup>th</sup> out of 177 countries on the United Nations Human Development Index, which ranks countries on how well they ensure the health, education and decent living standards of their people (DISE, 2007). In the less than 70 years that India has been a nation, the country has not yet been able to guarantee that all of its people, living in a wide range of circumstances, are able to secure the amount and quality of health care that they need and have the right to. Furthermore, in addition to lack of treatment, there have historically been many cultural ideas and social issues that have fostered intense discrimination against those with clefts in India and reduced their quality of life. There have been improvements in the past few decades in regards to community acceptance and experiences in receiving treatment, but even today there are many families in India who do not know that their child's cleft can be repaired or where they can go to receive affordable care, and therefore their child continues to suffer the physical and social challenges that clefts create.

Due to the month-long nature of this fieldwork project, only one small region of India could be examined in detail. After a review of the scholarly research surrounding the topic of clefts in India, it was concluded that there is a severe gap in knowledge about what factors affect the lives and treatment outcomes of people with clefts in the Nainital district in the Kumaon region of Uttarakhand state (UK). The rough terrain of Nainital, located in the foothills of the Himalayan mountain range, in combination with the socioeconomic conditions in which many rural residents live, has the potential to increase the difficulty of learning about and obtaining cleft care. General data has previously been collected about the troubles in accessing health care and the lack of knowledge about clefts in this region, but there is insufficient analysis of the range of challenges that cleft families face.

## **Project questions and goals**

Therefore, the proposed question for this fieldwork project was: what are the socioeconomic factors that influence the lives of people with cleft lip and or cleft palate in rural Nainital, and the treatment, or lack thereof, which they receive? The goal of this project was to discover the factors that serve to increase discrimination and decrease the acquisition of cleft care, and therefore better know what interventions would be most effective to reverse these trends and improve the lives of people born with clefts in Indian Himalayan villages. Because of the vast geographical, cultural, and economic diversity of the country, the findings of this project may not be applicable in other Indian settings.

## **Field study methods**

This project was conducted with the guidance and assistance of the Aarohi organization in the Satoli village of Nainital district. The staff at Aarohi work with rural Kumaon villages, and conduct biannual surgery camps that include plastic surgeons who repair clefts. Aarohi teams travel around the region and identify people who need care, telling them when and where to go to receive treatment. In helping with this project, Aarohi staff identified people who have received such care from their camps, as well as people who have been informed about the available treatments, but have not pursued care. Interviews were chosen as the primary method of data collection because hearing people talk about their personal stories and experiences was believed to be the best way to uncover the many factors that impact people's lives. Interviews were conducted with one plastic surgeon who treats clefts, one woman who has personal knowledge of a cleft patient and is also a nurse at an NGO-run hospital in rural Nainital, one adult CL patient, and the guardians of five cleft children. These interviews took place over the periods of March 25-

27, 2014, and April 16-23, 2014. With the assistance of an Aarohi translator, the interviews were conducted in a mixture of Hindi and Kumaoni, and lasted approximately 30 minutes each. The interviews with the plastic surgeon and the nurse took place at the Aarohi office in Satoli village, and two of the interviews with cleft families took place in their nearby villages. The interview with the adult cleft patient was conducted at the Aarohi office in Okhalkanda Block, and the remaining three interviews with cleft families were conducted in their nearby villages.

Each family was asked about basic social and economic indicators, followed by discussion based around prepared questions regarding the impact that the cleft has had in their lives, as well as their involvements with treatment. Different sets of interview questions were prepared for care providers and for cleft patients or families. Verbal consent was taken before each interview, and an audio recording of each conversation was made. To protect their anonymity, participants' names and the names of their villages will not be included in this paper. The information obtained from these interviews, in combination with census data, the Aarohi Annual Review 2012-2013, and secondary literature, served as the basis for this project, and was used to determine the social and economic influences on the quality of life and treatment experience of cleft patients.

### **Brief statement of findings**

This project found that there were numerous factors that combined to play a role in the way that cleft patients were received by their communities, and in the awareness, availability, and accessibility of treatment options. There was found to be very little knowledge about the causes and recommended course of treatment for clefts, leaving many patients to suffer the physical and social challenges of being untreated until they were

identified and linked to care at ages that were much older than medically necessary. It was also shown that isolated setting and low economic status made it more difficult for families to learn about and access care.

### **Cleft Statistics**

The global average for the number of people born with any type of cleft is about 1 in every 700 live births (Operation Smile, 2014). However, there is a wide variation in the occurrence of clefts among different ethnic groups. Asian and Native American populations have the highest reported prevalence of clefts (as high as 1 in 500), European-derived populations have intermediate prevalence rates (about 1 in 1,000), and African-derived populations have the lowest prevalence rates (about 1 in 2,500) (Dixon, Marazita, Beaty, Murray, 2011). The breakdown for the types of clefts varies between studies and regions, but is approximately 45 percent CLP, 35 percent CL, and 20 percent CP (Moghe, Mauli, Thomas, Obed, 2011). There are further differences in the frequency of the three types of clefts between males and females. CL has a male to female ratio of about 2:1, and CP has a male to female ratio of about 1:2 (Dixon et al., 2011). Unilateral CL is more common than bilateral, and for patients with unilateral CL, there is a 2:1 ratio of left to right sided clefts.

Although the Birth Defects Registry of India was established in 2001, sufficient data is still lacking, and the incidence of clefts in the Indian population is not precisely known (Sharma, 2013). However, it is estimated that between 28,000 and 35,000 children are born with clefts in India each year, or about 1 out of every 500 to 800 live births (Reddy S.G., Reddy L.V., Reddy, R.R., 2009; Singh, 2009). The numbers have been slowly improving, but until recently, only one-third of the new Indian cleft cases were corrected each year,

and only half of those cases were treated by a trained surgeon (Singh, 2009). Often, this disparity is a result of social factors that prevent people from knowing about available cleft care options, or the inability to pursue treatment because of the economic hardship that it would impose. As a result, there is a backlog of about one million untreated clefts in India (Singh, 2009).

In the present study, conversations with or about three females with CL, one male and one female with CP, and two males with CLP were conducted. Out of the seven cleft cases studied in this project, two cleft palates were not treated. One of the CLP boys had his cleft lip repaired at an Aarohi health camp, but has not returned to have his cleft palate mended. The second untreated case is the male CP patient, who also has Down syndrome. As will be further discussed later, there are numerous factors that have likely impacted this lack in CP treatment.

### **Causes of Clefts**

Researchers have yet to discover a clear cause of cleft lip and palate. It is generally accepted in the medical community that a combination of many genetic and environmental factors contribute to the formation of clefts (Dvivedi, J., Dvivedi, S., 2012). Studies have shown that if one sibling or one parent has a cleft, then the likelihood of a child being born with a cleft in that family ranges from 2.0 – 7.0 percent in a population where the likelihood of being born with a cleft if no sibling or parent has one is 0.04 - 0.1 percent (UC Davis, 2014). Evidence suggests that a lack of certain vitamins or exposure to tobacco smoke, alcohol, viral infections, and certain medications during pregnancy, may raise the risk of the child being born with a cleft (CDC, 2014). With the development of genetic analysis

technology, there has been a recent surge in studies searching for links between mutations on specific genes and the occurrence of clefts (Dixon et al., 2011). While there has been marked progress in identifying relevant genes and other risk factors, it appears that the fusion of the lip and palate is affected by such a large number of factors that one single cause may never be determined.

Although India is now classified as a lower-middle income country, its lingering poverty and insufficient public health system impact the issues surrounding clefts both before and after birth. In 2010, 394 million Indian people fell below the international poverty line of living on less than 1.25 US dollars per day, and 829 million people lived on less than 2 US dollars per day (World Bank, Poverty & Equity: India, 2014). The majority of families in UK are dependent on the agriculture of their small pieces of land, and the resultant low incomes contribute to their restricted access to education and health facilities, thereby creating a cycle of poverty (Mittal, Tripathi, Sethi, 2008). 47.1 percent of Uttarakhand's rural population was determined by the state to be Below Poverty Line (BPL) in the year 2002 (Uttarakhand Government Portal, 2014). Low-income mothers may be more exposed to some of the environmental factors, such as poor nutrition, tobacco, and infection, that increase the risk of having a child with a cleft (Mossey, Little, 2009). The lack of education, particularly health education, in India may also increase the likelihood of cleft births because women have never learned what to avoid and what to do to have the healthiest pregnancy possible. In addition, lower social and economic status and geographic isolation have been shown to be associated with fewer antenatal check-ups, during which women are informed about what they can do to reduce the chances of their child being born with a birth defect (Pallikadavath, Foss, Stones, 2004). 39 percent of

Nainital's people live in urban areas, and 61 percent live on rural land (District Administration Nainital, 2014). 36.7 percent of women in rural Nainital and 23.4 percent of women in urban Nainital do not receive antenatal care in the first trimester of pregnancy, during which time clefts are formed (Office of the Registrar).

### **Challenges of Life with a Cleft and Factors that Perpetuate them**

#### **Physical challenges**

Depending upon the extent of the split, people born with clefts can face a wide range of physiological and psychological challenges. After birth, one of the most immediate concerns for every infant is the ability to obtain adequate nutrition, particularly their mother's milk (Meyer-Marcotty, 2010). It is important for babies to gain weight and grow, and consuming breast milk improves infants' resistance to infections and reduces their risk of developing a wide range of chronic conditions later in life (UNICEF Breastfeeding, 2013). For cleft babies, it is especially vital to acquire sufficient sustenance in order to ensure that they grow to become strong enough to undergo and recover from repair surgery. However, the normal reflex that enables infants to rhythmically use their oral muscles to latch onto the breast, create a negative intraoral pressure, and achieve the necessary suction to drink milk, can be disrupted by clefts, chiefly cleft palates. One study found that 73 percent of CP infants had moderate to extreme breastfeeding difficulties related to their reduced sucking efficiency (Meyer-Marcotty, 2010). These difficulties included insufficient suction, excessive air intake, choking, nasal regurgitation, failure to gain weight, and excessive time required to feed.

Because of these issues, babies with severe clefts may develop malnutrition or the failure to thrive condition (Devi, Sai Sankar, Manoj Kumar, Sujatha, 2012). This classification is given to children whose weight or rate of weight gain is significantly lower than that of other children of the same age and gender (Medicine Plus, 2014). If the failure to thrive condition persists for a long enough time, the effected child often falls under the categorization of stunted growth (WHO, 2014). This means that the brain and body are not receiving enough nutrients to grow and develop properly, potentially leading to irreversible physical disabilities and learning difficulties (UNICEF UK). Research has shown that children with clefts have significantly lower height and weight during the first year of life, as compared to control children (da Silva Freitas et al., 2012). The subsequent effects of undernutrition during early childhood can lead to long-lasting growth problems, and may increase the risk for coronary heart disease and diabetes (Barker, Clark, 1997). Therefore, depending on the specific structure of each infant's mouth, bottle-feeding or spoon-feeding may be the most effective way for the child to attain adequate calories (Bessell et al., 2011). However, in addition to the consequences of not receiving the health benefits of their mother's milk, there are various challenges associated with non-traditional feeding techniques in different parts of the world, such as difficulties in accessing infant formula and safe water, the inability to sufficiently clean bottles so that they do not spread infection, and cultural stigma surrounding the issue (UNICEF Breastfeeding, 2013).

It is often more difficult for infants with severe CP who cannot breastfeed to obtain proper nutrition in India, particularly rural or urban slum India, than it is for comparably disfigured infants in many other parts of the world (Gopalakrishna, Agrawal, 2010). In contrast to doctors in higher-income nations who usually advocate for bottle-feeding, the

majority of Indian physicians who serve cleft families in rural areas recommend spoon-feeding when breastfeeding cannot sustain the child. Spoon-feeding can be more hygienic than bottle-feeding for rural Indians, as it is easier for them to keep cups and spoons clean than it is to ensure that bottles are safely sanitary. However, it takes more time to spoon-feed a baby than it does to bottle-feed them the same volume, and babies are more likely to swallow air while spoon-feeding (Nair, Narang, Mahajan, Arora, 1994). In addition, it can be very difficult for poor Indian families to find and pay for infant formula or to pump the mother's milk, so they may persist in trying to breastfeed, even when the infant is unable to drink enough milk and fails to grow and gain weight properly. This challenging situation that many cleft families in India face contrasts the options that higher-income families in urban India or in other countries have to easily pump their breast milk and to feed it to their children in bottles that are specially made to make it easy for cleft babies to successfully use.

In addition to difficulties feeding while the cleft remains untreated, children with clefts, particularly CP or CLP, are predisposed to a range of other complications that are present both before and after cleft repair surgery. For example, patients with a CP are more likely than unaffected children to have recurrent middle ear infections and inflammation that may lead to permanent hearing loss (Meyer-Marcotty, 2010). Due to breath exiting the nose as opposed to the mouth, and due to articulation problems resulting from misaligned teeth and abnormal shape of the lip and palate, it is common for cleft children to experience difficulties speaking clearly and with comprehensible pronunciation. Furthermore, another physical problem that children with clefts experience is increased incidence of dental caries attributable to poor oral hygiene, longer oral clearance time of foods, and drainage of nasal

fluids into the mouth (Cheng, Moor, Ho, 2007). Additionally, CP children's teeth may erupt in a highly misaligned fashion, and some teeth may never develop, leading to difficulties eating solid foods and an unattractive appearance. There may also be inadequate density in the alveolar bone of the palate to support the upper teeth and the floor of the nose, contributing to improper development and early fall out of teeth, as well as collapse of the nose and difficulties with nasal breathing (Winchester, Booth, 2001). These issues are not avoided by initial repair surgeries that mend the split in the bone, and may require extensive procedures such as speech therapy, alveolar bone grafts, and orthodontic care throughout childhood (Moghe et al., 2011).

In this project, speech was the only reported physical problem prior to treatment among those with CL. One father said that his CL daughter was unable to say whole words before her lip was repaired, despite the fact that she was three years old at the time (Guardian I, Personal Interview). However, all of the CP and CLP patients had difficulties breastfeeding and later eating. The father of the girl CP child stated that before she got treated, water, saliva, and food came out of her nose, and that when she tried to speak, the air exited her nose as well, making her unable to produce words (Guardian II, Personal Interview). His numerous mentions of his anxiety about his daughter's small size, in combination with her very small appearance, suggested that her growth was stunted due to her eating troubles prior to treatment. The father reported that she is now "becoming healthy," and that her speech and eating are much improved. In regards to physical problems after cleft repair, only one issue was identified and reported. The grandmother of a CL girl stated that sometimes when she cries, the girl's lip swells and bleeds (Guardian V,

Personal Interview). This problem is likely due to buried stitches causing an abscess, and needs the care of a medical professional to be amended (Shinohara, Matsuo, Kikuchi, 1996).

### **Social challenges**

Furthermore, besides causing physical challenges, untreated clefts are known to be one of the most unattractive deformities, and can therefore be a source of significant social distress (Murthy, 2009). Unrepaired clefts greatly mar the natural symmetry of the face, and draw substantial attention from the viewer. It is well established in academic literature that facial symmetry is one of the most important determinants of how attractive a person is perceived to be (Meyer-Marcotty et al., 2010). This applies not only to physical attractiveness, but to social attractiveness as well. People subconsciously use facial characteristics as a means of judging other peoples' overall physical attractiveness, desirability as a friend or romantic partner, and personality (Eliason, Hardin, Olin, 1991). Persons whose faces deviate from normal are perceived as less intelligent, less friendly, and possessive of undesirable personality traits. As a result, parents may be ashamed to show their newborn cleft baby to their friends and family, cleft children may face teasing from their peers, and young women may find it difficult to meet a man who is willing to marry someone with an untreated cleft (Murthy, 2009).

Moreover, even when the cleft itself is mended, scars on the lip or remaining nasal or dental disfigurement immediately reveal to every person who sees the cleft patient that that person is different. Observers' eyes spend more time focusing on the nose and mouth of people with repaired CLP as compared to people without any deformities (Meyer-Marcotty et al., 2010). People with lip scars are rated less socially preferable as compared to people with other physical disabilities or obesity, and an aberration from normal

symmetric morphology in this part of the face has been shown to be the most likely feature to cause teasing during childhood (Eliason et al., 1991; Meyer-Marcotty et al., 2010).

Additionally, people may assign negative judgments to those who have or have had clefts due to their invisible speech or hearing problems.

The consequences of these adverse perceptions on people with clefts may include the discomfort and violation of privacy that come with extensive staring, social inhibition and a lack of friends, and resulting loneliness and low self-esteem (Eliason et al., 1991). Research has shown that in social situations, people who have repaired clefts approach their peers fewer times, are approached by their peers fewer times, make less eye contact, and slouch more often than unaffected people (Kapp-Simon, 1995). Thus, cleft patients may be more likely to drop out of school early or further isolate themselves from society, reducing their future earning potential and making them even more prone to low self-confidence, anxiety, and depression (Millar et al., 2013). Numerous studies have found that children and adults with repaired clefts report lower health related quality of life scores than unaffected people, that CLP adults report lower income, lower marriage rates, and older age at marriage than unaffected people, and that people with clefts report more psychological and social challenges than unaffected people, demonstrating the life-long adverse impact that being born with a cleft has (Wehby, Cassell, 2010).

As in other countries, social factors impact the health of Indian cleft patients by influencing the way that their communities, and subsequently their parents, view their deformity and act upon what they see. Many Indian families, like families in other countries, are ashamed to let their community see their child, and therefore keep them in solitude (Murthy, 2009). One study found that while 64 percent of Indian parents did not

limit their cleft child's social interaction and were not ashamed for them to be seen in public, 26 percent exercised some social constraints on the child, and 10 percent kept them completely isolated (Weatherley-White, Eiserman, Beddoe, Vanderberg, 2005). Dvivedi's research (2012) in the Garhwal region of UK discovered that cleft children there were called "*Khandu*" (incomplete) by the rest of society. Another study found that some Indian cleft children are refused admission to school on the basis that their appearance would frighten the other children (El-Shazly et al., 2010). Furthermore, many Indian people with clefts and cleft scars cannot find jobs or get married due to the way that they look (SmileTrainIndia). In several studies that examined the expected outcomes of cleft treatment surgeries, most parents stated that their main goals were increased opportunities to attend school for both their sons and their daughters, and greater prospects of marriage for their girls (Weatherly-White et al., 2005).

In addition, the use of prenatal ultrasound technology is rapidly increasing across India (Imaging Economics, 2013). Many experts predict that this trend may lead to ever rising numbers of abortions due to families not wanting a child who has a cleft, similar to how some parents have been known to kill or abandon their cleft child at birth (SmileTrainIndia). Numerous studies have shown that there is poor acceptance of people with facial deformities in India, especially in rural areas where there is less education and health awareness (Reddy et al., 2009). Conversely, other research has found that in comparison to people in other countries, Indians place more value in deeds than in physical appearances (Kadagad, Pinto, Powar, 2011). This prioritization leads people in some Indian communities to find no reason to abort a fetus because of a nonlethal birth defect, and may

contribute to the large numbers of unrepaired adult cleft patients in India, as these people see no reason to seek treatment for clefts that do not cause severe functional problems.

Although people who appear abnormal are often treated badly in every part the world, lack of knowledge about the disfigurement generally increases negative judgments (WHO, 2011). If more people were conscious of the medical facts behind birth defects such as clefts, there would likely be much less maltreatment of those people who look different. There are numerous issues in the primary education system in India, in which it is intended that children learn the basics of health, and as a result, the majority of Indian people receive substandard health education. For example, while close to 90 percent of Indian children ages 6-14 years old are formally enrolled in primary schools, nearly 40 percent drop out at the primary stage (DISE, 2007). In a World Bank study, an average of 25 percent of government primary school teachers in India were found to be absent from work, and only 50 percent of teachers were actually engaged in the act of teaching while at work (World Bank, 2013). Uttarakhand was found to have one of the highest rates of teacher absenteeism, at 30-34 percent. The resulting ignorance about health issues such as birth defects contributes to the discrimination that people with clefts in India receive, and hinders awareness about the fact that clefts can be mended with a relatively simple procedure.

Both similar to the literature, as well as contradictory trends have emerged from personal interviews. One of the fathers of cleft children stopped going to school after finishing the 5<sup>th</sup> standard, two stopped after the 8<sup>th</sup> standard, and one completed the 12<sup>th</sup> standard. However, the fact that none of the fathers remembered learning anything about

health while in school may be a reason why there was no noticeable trend between paternal education level and the quality of life and treatment of the children.

The adult woman who was born with a CL stated that she did not remember any discrimination from her community as a result of her cleft, and does not believe that she has suffered any problems in her life because of it (Adult Patient, Personal Interview). After her lip was repaired at age 2, she was able to attend a government school until the ninth class, and then she got married, and was chosen by her community to be an Accredited Social Health Activist (ASHA). Similarly, the mother of one of the boy CLP patients, who had surgery for his lip at age 1, shared that there had never been a problem with anyone who saw the boy saying anything negative about his cleft lip (Guardian IV, Personal Interview).

On the other hand, the majority of people interviewed for this project had experience with family and community members making adverse comments regarding the appearance and physical issues of the cleft children. One CL girl went to a school for small children, but before her lip was repaired, the other students always laughed at and talked about her (Guardian I, Personal Interview). This child's father stated that in his opinion, the hardest part about the time prior to her treatment was the idea of what would happen to his daughter when she got older, particularly if he would be able to find a husband who would accept her with her disfigurement. His family shared this concern, leading the girl's grandmother to try to find a place where she could receive affordable care. Likewise, the other CL girl's grandmother said that neighbors used to comment that this child will suffer in the future because of her cleft, but that now that her lip is mended, it presents much less of a problem (Guardian V, Personal Interview). She also said that her daughter in law, the CL child's mother, was herself born with a CL, and that she got hers repaired 2 or 3 years

before marriage age because although it had not caused her serious physical challenges, her family knew that it would be significantly easier to get married with scars on her lip than it would have been if she had a cleft lip.

Furthermore, although no one could see the hole in the female CP child's mouth before she was treated, it was evident that she could not speak, and that water, saliva, and food came out of her nose uncontrollably (Guardian II, Personal Interview). These factors led other children to tease this girl, causing her to be too frightened to go to school. Now that she can talk, and that the large opening between her nasal cavity and her mouth is closed, this girl attends school and has made friends. Enough of her fears and speech difficulties persist, however, to cause her to be too shy to speak to her teachers in class. Similarly, the interviewed nurse said that cleft people in her community are often intensely made fun of (Nurse, Personal Interview). However, she thought that once people's deformities were treated, they usually went on to lead much more normal lives. She told a story about how a boy from her village was born with a CLP, had it repaired when he was young, grew up to attend college, and will soon be married.

The plastic surgeon, who has given care to cleft patients for many years, has seen that there are many differences in the way that people with clefts feel about themselves (Plastic Surgeon, Personal Interview). In some cases, people live with cleft lips for all of their lives, and do not feel hurt by the teasing that they receive. Other times however, the appearance and speech problems that people with clefts have generate such hurtful teasing that they do not participate in school, become withdrawn, and suffer the effects of a lack of supportive community and education. Furthermore, the plastic surgeon has also observed that in comparison to people with other types of birth defects, people with clefts seek

repair procedures significantly more often. The way that family and friends react with aversion when they see a baby with a cleft is very powerful in motivating parents to seek treatment, and unlike many other disfigurements, clefts are nearly impossible to hide with clothing.

In addition, the plastic surgeon has often seen parents of CLP patients only want to get the cleft lip repaired, and not care as much about the cleft palate as long as it does not cause considerable difficulties in function. The comments and repulsed staring of family and friends compel many Indian parents to seek treatment for the CL, but because observers cannot usually see the CP, there is significantly less social pressure to repair it. Accordingly, these parents are much less motivated to spend the necessary money and bear the burdens of pursuing care for the relatively hidden CP. The surgeon has seen many cases of young women coming to seek treatment for CP soon before they are to be married because it had not caused them significant problems before, but they do not want their husband to know about it. However, while lip repair significantly reduces the social pains that clefts cause, they leave CLP patients to suffer from the eating, speaking, hearing, and breathing challenges that cleft palates can produce. The doctor has learned through his years of practice that it is best for the health of the patient to have both the lip and the palate repaired as soon as possible. As a result, he usually reverses the traditional order of CLP treatment and mends the palate first, knowing that most parents will take the initiative to return to the treatment center to have the lip repaired once the palate has healed.

Moreover, there are many studies on cleft lip and palate in India that analyze differences between the lives and treatments of male and female cleft patients. Most studies have found that greater numbers of boys than girls seek treatment for clefts

(Dvivedi, J., Dvivedi, S., 2012). One reason for this trend is that more boys than girls are born with clefts. However, out of the pool of affected people, a higher percentage of boys receive surgery than girls, possibly because male children are traditionally better taken care of and are more visible to the outside community than are female children in Indian society (Bhungalia et al., 2013). However, other studies have found that more girls seek repair surgeries than boys due to parents' worries about their ability to find marriage partners for their daughters with untreated clefts (Singh, 2009). It is possible that the contradictions found in various studies stem from a trend for more male cleft patients to receive treatment at an early age, and for a greater proportion of female patients to receive care shortly before marriage age, as well as from social differences between Indian communities.

Each of these various views about gender differences were found in the present study. While all of the guardians of the young girls with clefts expressed social and marital concerns, the adult CL woman said that she had never experienced any social stigma because of her appearance (Adult Patient, Personal Interview). As previously mentioned, the mother of one of the CL girls had her own CL mended shortly before she was old enough to be married to make it easier to find a husband. Also, the lack of treatment in the two male cases of CLP and CP are in spite of significant physical problems with eating and speaking. The family of the CLP boy has repeatedly been pressured by Aarohi staff to return for palate care, but has yet to agree even after learning that their son's challenges will only worsen as he gets older. Neither guardian of these two untreated boys spoke of any social issues that were a result of the CP, and in none of the four female cases was any cleft repair unattained. Therefore, even though only one female with a CP was identified in this project,

it should be considered that one factor that may influence whether or not clefts are treated and when they are treated, is the gender of the patient. Community members may make fewer negative comments about male cleft children, and the parents may not be as worried about future marriage than they would be if their cleft child was female, thus making them less motivated to pursue care.

### **Challenges Obtaining Treatment and Factors that Perpetuate them**

Despite the fact that people have been studying clefts and refining the repair procedure for hundreds of years, there has yet to be developed one global set of standards for the most effective methods in which to carry out cleft treatment (Moghe et al., 2011). However, it is generally recognized that optimal cleft care involves a multidisciplinary approach coordinated by a team of professionals. Immediately after birth, parents should be given individualized advice and coaching on the best way to feed their baby based upon the structure of the infant's mouth and the resources available to the parents. Ideally, growth should be closely tracked to ensure that the infant is consuming sufficient nutrition. Hearing evaluations of those with CP should begin around 6 weeks after birth, and cleft lips should be repaired between 1 to 6 months of age. There is more variation in the prime time to perform palatal surgery due to the wide scope of severities, but it is largely advised to have CP repair prior to the development of speech patterns and habits, preferably in the 6 to 18 month range (Plastic Surgeon, Personal Interview). In addition, dentists, otolaryngologists, and speech therapists should monitor cleft children for suggested care starting at age 1 year, and orthodontists should consult with patients by age 6 years (Moghe et al., 2011). In cases where alveolar bone grafts are necessary, surgeons should

perform these operations between ages 6 and 10 years. Jaw surgery if the bone is too small, restorative dental care if there are missing teeth, and nose operations to improve breathing or appearance should be conducted once the patient has stopped growing at around 18 years of age.

However, despite the ample evidence that treating patients as soon after birth as possible leads to the greatest improvements in life-long health, most Indian patients who seek surgery are much older than the target age (Gupta et al., 2010). Studies have revealed average treatment ages ranging from 2 to 10 years old, with as many as 27 percent of patients trying to get care for the first time between 10 and 35 years of age (Gupta et al., 2010; Moghe et al., 2011). The results of the present study may not be representative of the average treatment ages in rural Nainital district because the patients were identified by the Aarohi organization, which advocates for health care in the specific villages that is it connected with. This being said, primary cleft treatment was received at age 1 year for one patient, 2 years for one patient, 3 years for two patients, and 4 years for one patient. Still, as previously noted, one CLP patient has yet to receive CP repair, and one CP patient has not received any cleft care.

### **Awareness of and motivation to pursue care**

One of the most influential reasons that cleft patients, particularly in rural parts of India, do not receive care is the lack of awareness about the surgery that will greatly improve the rest of their lives. There are numerous missed opportunities for learning about cleft care that begin at birth. Many Indian women give birth with only their untrained family members to assist them, and there is great disparity in birth setting between socioeconomic levels. While 23.6 percent of India's poorest 20 percent of people give birth

with a skilled attendant, 84.9 percent of India's richest 20 percent do so (UNICEF Statistics, 2013). Furthermore, 55.3 percent of women in rural Nainital have institutional deliveries, as compared to 70.5 percent of women in urban Nainital (Office of the Registrar). 44.9 percent of home deliveries in rural Nainital are conducted by skilled health personnel, as compared to 69.4 percent of home deliveries in urban Nainital.

The Janani Suraksha Yojana (JSY) program was created in 2005 for the purpose of trying to increase the number of institutional births by providing BPL women with 500 rupees if they give birth in a health center (National Health Mission, 2013). In addition, each ASHA, local women to whom the government provides basic health training, is told to try to encourage the women in her village to give birth at health centers, and is given up to 600 rupees for every woman that she brings to an institution for birth (Bajpai, Dholakia, 2011). With its elevated focus on ASHAs, the Indian government has recently been giving less attention and training to home birth attendants (Devraj, 2009). Many people condemn this change because in some parts of India, particularly in rural areas such as in Nainital, many women are much more comfortable with the idea of giving birth at home than of going to a hospital, and there are many places in which it is very difficult for women in labor to access treatment centers in time. The previously given statistics show that there are still many women who do not take advantage of the JSY incentive, that there are many ASHAs who do not succeed in bringing every pregnant mother to a health center when it is time for her to give birth, and that there is not a sufficient system of trained home birth attendants. As a result, many cleft children are born at home without any health professional present to instruct the family on how to care for the child, or to give them the

knowledge of where they can go to obtain treatment. In this project, all of the cleft children were delivered at home, and at none of the deliveries was a trained attendant present.

In addition to opportunities for families to learn about how to best care for their child immediately following birth, the Ministry of Health and Family Welfare launched the Rashtriya Bal Swasthya Karyakram (RBSK) program in 2013. Under this program, every ASHA is instructed to visit each home in her assigned village and screen every child for 30 identified health conditions, one of which is cleft lip and palate (Ministry of Health and Family Welfare, 2013). If she finds a child with a cleft, the ASHA is supposed to inform the family that there is a place where they can go and receive free quality care that will be very beneficial to the current and long term health of their child. However, this system of cleft identification and linkage to care is not flawless either, and remains in the development process. Though under the National Rural Health Mission (NRHM), every village is meant to have an ASHA, some ASHAs are not aware of and do not properly execute all of their assigned duties, and it is not uncommon for many people to be ignorant of who their local ASHA is (Rao, Dholakia, 2011). In none of the seven cases in this project were any of the cleft children identified by an ASHA or informed of treatment options.

Furthermore, there are many issues with the health care system in India that make it unlikely that many cleft patients will be identified and informed about care options by doctors or nurses. 10 percent of the posts for doctors at Primary Health Centers and 63 percent of the specialist posts at Community Health Centers remained unfilled in 2010, and the quality of the medical staff that the majority of people in rural Nainital can afford to visit is often poor (Rao, Mant, 2012). For example, although the boy who has both Down syndrome and a CP has seen numerous doctors on account of the Down syndrome, none of

his physicians identified his CP, leaving his father to discover the hole on the roof of his son's mouth himself when the boy was about 8 years old (Guardian III, Personal Interview). This father said that he has not gone to see a doctor regarding his son's CP because he did not know that this cleft was causing any of his son's health problems as opposed to the Down syndrome being the cause. After spending significant time and money trying to cure the Down syndrome, the father was told that it cannot be cured, and that he should stop spending money on treatment because he is poor. However, now that he has learned that his son can receive care at Aarohi that will improve his health and quality of life to some degree, he plans to attend the next multispecialty health camp that Aarohi holds.

The consequences of the issues in the Indian medical care system contribute to the fact that most Indian cleft patients who seek treatment state that they were previously unaware that their condition could be fixed, and that some do not know that any other people in the world are affected by the same problem (Moghe et al., 2011). This ignorance is also in part a result of low levels of health education and high rates of illiteracy. In some rural villages where people do not watch television or read newspapers which may contain advertisements for cleft care facilities, the only way for families to become aware of the realities of cleft causes and treatments, is if a neighbor or relative has travelled to a community where they have learned about clefts, or if a Non-Governmental Organization (NGO) seeks out and identifies cleft patients in their area (Singh, 2009). While in some parts of the world, the vast majority of children are born in hospitals and are immediately linked to care if they have a birth defect, and most parents take their children to see doctors for regular check-ups and whenever they are sick, this is not the case for the majority of families in rural Nainital. Dvivedi's research (2012) in the Garhwal region of UK

found that awareness of and concern about cleft treatment were particularly low in the hilly areas, that many of the cleft patients in that area received care at later than ideal ages, and that most of the families gained information about treatment from newspaper advertisements.

In the present study, although there were variations in the languages spoken by the interviewed families, no associations between language and cleft repair were observed. All of the families have lived in the same area for many generations, and only two of the families knew of another person with a cleft. Both of these families sought treatment on their own before Aarohi identified and informed them about their camps. In one case, the known cleft person was an acquaintance from a nearby village who had received treatment for her CL many years ago when she was young (Guardian I, Personal Interview). The other case was the CL girl's own mother who had also had a CL (Guardian V, Personal Interview). Because there are so many other influential factors, it is impossible to know whether or not these two families would still have taken the initiative to pursue care without having been told about it. However, being aware of the fact that other people have successfully been treated for their same problem is likely to have had some impact on the decisions that these families made.

Out of the seven cleft stories obtained in this study, four of the families sought treatment somewhere, but for a variety of reasons were not able to receive care at that location. For one of the families, the reason was financial, and this will be further discussed later. Another family went to an NGO that did not have the necessary specialized staff to perform the cleft repair, so the NGO referred the family to a government hospital 300km away. The two other families were given poor quality information. Of these two families,

one took their CL daughter to a government hospital for treatment when she was 2 months old, and was told that her lip could not be mended until she was 3 years old (Guardian I, Personal Interview). Despite the fact that most plastic surgeons will repair CL as young as 1-3 months old, the information that this family received prompted them to not seek treatment again until they were identified by Aarohi staff, causing the child to suffer from her cleft for about 3 years longer than medically necessary. In a similar case, the family of another CL girl took her to a government health camp in a nearby village, hoping to be able to receive treatment (Guardian V, Personal Interview). While there, the family was told that only the clefts of newborn babies or of children older than 2 or 3 years could be repaired. This girl was no longer a newborn, but was not yet 2, so she also returned home untreated. These families were motivated to seek care for their daughters, but neither was aware of the medically proven norms of cleft treatment, or of any other location where they could try to obtain care. Therefore, they had to rely upon the false information that was given to them, leading them both to prolonged physical and social pain.

Similarly, while the families in this project do not know what the specific anatomical problems that their children have are, they experience the current issues, and fear the future. With their limited health education and specific knowledge of clefts, however, it is doubtful that they are aware of the future structural and dental problems that often arise in CLP and CP patients and complicate their health, whether the cleft has been mended or not. Consequently, it appears unlikely that these families will pursue orthodontic or dental care, putting their children at an elevated risk for unsightly and dysfunctional teeth and noses.

In addition, local variations in the health education that people receive and the myths regarding the causes of clefts that are passed down through generations, as well as

the local cultural acceptability of cleft treatment, have a direct impact on the perceptions of people with clefts and whether or not patients obtain repair surgeries. In certain Indian localities, there is a prevalent belief that children are born with clefts because their mother was outside or was handling a sharp object during an eclipse when she was pregnant (Moghe et al., 2011). Further commonly cited causes are that a spell was cast upon the mother, or that an envious person cast an evil eye. In these cases, parents often take cleft infants to holy men or swamis to try to thwart the evil eye, rather than to medical doctors for cleft repair. In other studies, the majority of families cited the cleft as “God’s will,” or a punishment for the sins of one of the parents (Weatherly-White et al., 2005). In places where parents believe that it was their own past sins that caused their child to be born with a cleft, the ensuing guilt may precipitate the parents to hide the child from society and not take them anywhere for treatment because this would announce to their peers that they were sinful (el-Shazly et al., 2010). This shameful burden that the cleft child unconsciously places upon their parents, combined with the potentially lifelong burden that the son or daughter would be if they were unable to get a job or get married due to the cleft, may foster animosity between parent and child and lead to maltreatment or abandonment of the cleft child. This mentality, that God is in control of nature, leads other parents to resign to the idea that God wants their child to be this way, and therefore believe that there is no point in trying to find a way to change the child’s God-given facial structure. Moreover, in one study, several parents were concerned that if their present child’s cleft was repaired, God would punish one of their future children with a cleft (el-Shazly et al., 2010). In this case, treatment would not be acceptable because it would cause another cleft in the future.

However, in places where clefts are merely seen as random and ugly disfigurements, parents may be more likely to seek treatment in order to escape the social and physical pain that clefts generate (Murthy, 2009). Environmental factors are rarely considered as potential causes of clefts in India, and even in cases in which other family members have had clefts, the influence of family history or genetics is seldom thought of (el-Shazly et al., 2010). The unfamiliarity with these scientifically proven causes of clefts among much of the Indian population is in stark contrast to the awareness of residents in other parts of the world in which modern medical knowledge is more widespread. In areas where it is common knowledge that birth defects have genetic and environmental roots, people may be less likely to stigmatize or isolate cleft patients because they know that their appearance is not a result of any ill-action of themselves or their parents. Despite lingering concerns among some Indian populations about modern western medicines, few studies have suggested any cultural resistance to the cleft repair surgery itself (Reddy et al., 2009). On the contrary, once the defect is corrected, people with clefts are generally much more accepted among family and peers.

Here again it is clear that there is much variation across India. The surgeon said he has seen that the belief that the cleft is mother's fault is prominent both in more developed and less developed parts of India (Plastic Surgeon, Personal Interview). He explained the common eclipse myth by saying that if a pregnant woman uses a knife for any purpose or uses her nails to even scratch her arm while there is a solar or lunar eclipse, there is the belief that her child will be born with a cleft. The NGO nurse thought that the mother of a cleft baby might have taken some medicine that she was not supposed to take while she was pregnant, or that it was simply the will of God and was not a result of any action or

inaction by the parents (Nurse, Personal Interview). Dvivedi's study (2012) in the Garhwal region of UK found that the belief that clefts are a curse from the gods was prevalent in the remote sections of that area. In the present fieldwork in Kumaon, one family believed in the idea of an eclipse causing the cleft, one family thought that the cleft was either a result of God's will or because the child's mother also had a cleft, and the remaining families said that they had no idea why the child was born this way. None of the families had considered that environmental factors might have contributed to the formation of the cleft. There were no noticeable trends discovered in this project showing a relationship between different parental beliefs about the cause of clefts, and how parents regarded their children or the manner in which they pursued cleft care.

Out of the 7 cleft patients discussed in this project, only 2 of them learned about and received care solely due to the efforts of their families to search for treatment. Of the remaining five, two families learned about Aarohi's multispecialty surgery camps through advertisements posted in their villages, two were identified by Aarohi health staff conducting home visits to recruit patients for the camps, and the boy who has both Down syndrome and an unrepaired CP, was identified when an Aarohi staff member came to the home on business unrelated to health. These families were all very fortunate to be of the 36,800 people living in the 58 villages that Aarohi has targeted (Aarohi, 2013). However, in addition to their luck of being within the reach of an NGO that performs cleft repairs, these families had enough motivation, resources, and available time to make the trip on behalf of their children. Despite Aarohi's advertising and outreach, there are still many identified patients who do not attend the camps and receive care "for reasons of poverty and their own inhibitions created by life situations," (Aarohi, 2014).

## **Availability and accessibility**

As previously discussed, clefts are a deformity that can cause numerous and wide ranging health problems necessitating complicated and comprehensive treatment over the course of childhood in order to be properly amended. However, India does not have a large enough network of speech therapists, orthodontists, dentists, oral surgeons, and otolaryngologists to reach all of the cleft patients scattered across the nation (Plastic Surgeon, Personal Interview). Although there has been significant improvement in the past decade, clefts have generally been looked upon in India primarily as a cosmetic problem, rather than a functional issue (Reddy et al., 2009). Even in large hospitals that do employ specialists that can work with cleft patients, it is uncommon for there to have ever been any protocol developed for determining the different steps to be taken with which patients and at what ages (Moghe et al., 2011). The focus has historically been only on repairing the split in the lip or bone, with very little attention given to speech, dental, hearing, or nasal breathing difficulties. This mentality, in combination with the vast disparity between the number of patients in need of care and the number of well-trained personnel, as well as the lack of infrastructure and financial resources, has created a situation in India in which the multidimensional cleft teams that are ubiquitous in other countries rarely exist and even more rarely are accessible to those who require their attentions.

In regards to people's ability to receive the initial cleft repair itself, this level of care has also historically been very difficult for the majority of India's impoverished patients to obtain. Until recently, India has had very limited cleft treatment services available (Reddy et al., 2009). Although government hospitals are often more numerous, are easier for people to reach, and offer less expensive treatment than private services, their care is

generally of a lower quality, and public hospitals are often overburdened by the large proportion of patients to doctors who are competent at performing cleft surgeries (Moghe et al., 2011). Due to the poor quality of care, significant travel distance to reach services, extensive wait times, and inconvenient operation hours of publicly run services, about 70 percent of urban families and 63 percent of rural families choose private medical care over public (Ministry of Health and Family Welfare, 2007). Although 69 percent of the Indian population lives in a rural area, only 20 percent of hospital beds are in rural areas, and in some places there is only one healthcare provider with a degree for every sixteen villages (Kapil, Choudhury, 2005).

One study found that more than half of Nainital's rural population does not have access to health facilities (Thaplyal, 2012). The difficulties that the rough mountainous roads pose to travellers force most of the people who live in Nainital district to seek health care at the nearest location to their homes (Basu, 2012). Many Indian medical professionals prefer the high technology and urban lifestyle of major hospitals located in large cities, and consequently do not live and provide health services in the isolated and rural communities of Nainital. As a result, the farther that people with clefts live from an urban center, the smaller the likelihood that there is a treatment center within a feasible distance from their home that is equipped to care for their needs. People often find that the most conveniently located care provider is one of the uneducated quack doctors who are proliferating in the region (Dvivedi, J., Dvivedi, S., 2012). These quacks generally either do not assist their patients in any way, or cause them more harm than good. They are unable to meet the complex and varied needs of cleft patients, so families who go to them waste their precious time and money on unhelpful and potentially harmful services. These isolated patients are

forced to travel greater distances to reach quality care, and take more time off of work, spending more money on travel expenses, to get there.

Although none of the families in the present project spoke of visiting a quack, it was not easy for any of them to reach their care facilities. None of the families had their own vehicle to use as transport. One family walked for several hours, one paid to take a bus round trip, and two were able to take advantage of an Aarohi vehicle on the way to the hospital, but paid to return home in a bus. If they had not learned about the Aarohi surgery camp, these families would either have had to find a way to travel a much farther distance, such as the family who was referred by a different NGO to a government hospital 300km away, or may not have received care at all.

Furthermore, it must be considered that even if there were enough cleft specialists available and physically accessible to care for each cleft patients' problems, most Indian families would greatly struggle to pay for their services. Some potential reasons behind this could be the wages that would be lost in spending the time to go and receive care, and the number of trips and the distance that would need to be travelled each time to obtain full treatment. In order to have the cleft repair surgery, a family must take the time that could have been spent earning money to travel to the hospital, spend several days there, possibly pay fees for the procedure, medicines, lodging, and travel, depending on whom they receive care from, and travel back to their home. These expenses can be too large for many families to afford, contributing to the statistic that health care expenses are the second major cause of indebtedness among the Indian rural poor (Jat, 2014). In India, where about 829 million people live on less than US \$2 per day, the average cost of surgical repair for uncomplicated clefts is between 25,000 rupees (about US \$417) and 50,000 rupees (about US \$834)

(Reddy et al., 2009). Therefore, the costs associated with obtaining treatment are a substantial burden for many Indian families to bear, and are often a primary reason that prevents families from providing their cleft child with both the initial repair surgery and any follow up care that they need.

This common difficulty became evident over the course of the present project. The NGO nurse stated that she believed that it was especially difficult for poorer people to receive care, and explained that it was “very expensive” for the CLP boy from her hometown to receive the two necessary operations at the government hospital that his family took him to (Nurse, Personal Interview). Moreover, the family who took their CL girl to a government hospital but ended up not having her treated there, decided to return home because they were told that they would have to pay 15-20,000 rupees (Guardian I, Personal Interview). This family said that their entire annual income is 15,000 rupees. The total price of all treatment-related costs for the interviewed families who obtained care at Aarohi camps was 4-5,000 rupees, 5,000 rupees, 6,000 rupees, and 13,000 rupees. These families are all Below Poverty Line (BPL), with one of the fathers being a farmer, one a carpenter, one a driver, and one a local laborer. Therefore, even though their care was highly subsidized by Aarohi, each of these families needed to borrow some money from friends or family in order to be able to pay for their treatment.

Furthermore, the pain of this financial burden may be influencing two of the families to not pursue additional care. As previously mentioned, the lip of one of the CL patients sometimes swells and bleeds when she cries, despite having been treated 2.5 years ago (Guardian V, Personal Interview). Her grandmother said that the family is concerned about this problem because the girl will need to move to another home and live with different

people when she gets married. However, despite these worries, the facts that this issue does not occur very frequently and that the family does not have a lot of money, make pursuing further care a low priority for them. Similarly, the CLP boy whose CL has already been repaired still experiences numerous physical challenges as a result of his untreated palate, and in addition to this being uncomfortable, it leads his family to worry about his future (Guardian IV, Personal Interview). Yet, even though Aarohi has repeatedly pressured this family to bring the boy for CP repair by telling them that his problems will only get worse as he ages, the family has been very reluctant to do so. Their reasons for not going back for care are not being able to take the necessary time away from working and their lack of money. This is the family that paid 13,000 rupees the first time that they were there. When they arrived, the child had a fever that needed to be treated before the CL surgery could be done, so they ended up being away from home for 13 days. This experience of spending significant time and money on care, as well as the fact that the cleft in the palate is not immediately visible, has made further repair a low priority for this family as well. These families know about available care that will improve the lives of their children, but there are too many other factors hindering their ability to provide them with the treatment that they need.

Fortunately, there have been recent developments in making cleft care more economically and physically accessible in India. There has been a rise in NGOs providing free or relatively inexpensive cleft care all across India, and under the new RBSK, hospitals are required to provide corrective cleft surgeries free of charge. In addition, along with the NRHM's ASHAs, the Integrated Child Development Service's anganwadi workers are spreading awareness of the health care services that the government supplies, and are

linking patients to that care. Although about 86 percent of health care spending in India is out of pocket, there has been a large increase the numbers of Indians with some form of health insurance over the past several years, so this number is likely to drop significantly (World Bank, Poverty & Equity: India, 2014; World Bank, 2013). One insurance scheme that is having a substantial impact on many poor families is the Ministry of Labour and Employment's Rashtriya Swasthya Bima Yojana (RSBY) program, launched in 2008 (Rashtriya Swasthya Bima Yojana, 2009). The RSBY annually provides 30,000 rupees to BPL families to spend on quality hospitalized medical care, and the food, lodging, and transportation associated with that care. Contrary to the method in which the government counts families as BPL, based on income limits of 816 rupees and 1,000 rupees per capita per month in rural and urban locations respectively, the RSBY determines eligibility to the program based on what its developers regard to be more practical measures of poverty (DH News Service, 2012). This program is only available at treatment centers that the government has deemed to be of a high enough quality. The Aarohi hospital has recently been approved for RSBY, so it will be significantly easier for BPL families to receive affordable care at their upcoming health camps (Aarohi, 2014).

Many of these valuable insurance programs are new and imperfect, and many families who live in isolated areas have yet to learn about them. For example, the family whose annual income is 15,000 rupees should not have been charged 15-20,000 rupees for a cleft repair procedure, but evidently none of the government safety net programs were applied to this family when they were given an estimate of the cost. However, every day more and more people become aware of the fact that they now have easier access to medical treatment. Because more care is available and affordable, and more families are

learning of the existence of this care, India is now capable of treating more cleft cases each year than there are new people born with clefts (Smile Train India). As a result, the backlog of untreated cleft patients can begin to decline.

## **Conclusions**

This project sought to determine what social and economic factors influence the way that people with clefts live within their families and communities, as well as their experiences with cleft repair. The study was conducted in India, with a specific focus on the issues relevant in the rural villages in the Nainital district of Uttarakhand state. Over the course of this project, it became evident that cultural influences, economic influences, social challenges, and treatment outcomes were all connected with one another. The study reveals that the common lack of medical supervision and advice given during antenatal and postnatal periods was detrimental in part because women were not instructed on practical ways to prevent their child from being born with a birth defect, were not taught how best to care for the special needs of their new cleft infant, and were not linked to cleft repair facilities. In addition, analysis of the data suggests that the fact that many families in rural Nainital receive very little health education has a multidimensional impact on cleft patients. Women do not know what steps they can take to help to prevent birth defects, they are not aware that disfigurements such as clefts are extremely common and are relatively easy for trained doctors to mend, and people who have not been taught about deformities are much more likely to think and act towards them in a negative manner. As a result, clefts that may have been prevented are not, and children remain untreated, suffering from both the physical challenges of their clefts, and the hurtful conduct of their community members.

Furthermore, this fieldwork demonstrates that the isolated and hilly terrain of Nainital has a negative impact on cleft patients. There is a lack of well-trained medical staff who are capable of performing initial cleft repairs or of providing follow-up care for the many potential health problems that clefts can cause, and who are willing to live and work in the mountainous area. This leaves many families to obtain false information from unqualified people, or to bear the burdens of travelling extensive distances to receive good care. Also, unlike in more densely crowded areas, families in rural Nainital are not exposed to many other people with clefts, so they do not have the example of successfully treated neighbors to motivate them to also seek care. It is not uncommon for families in this region to be unaware of the fact that there are other people in the world who have the same problem, and many do not know about cleft care options even when they are available nearby. Additionally, belief in traditional myths as to the cause of the cleft and differences in the ways that communities view males and females may play a role in whether or not families seek cleft treatment for their child. Moreover, the issue of money seems to exert a powerful influence on whether or not people with clefts obtain treatment. In theory, the Indian government's RBSK and RSBY programs should ensure that every person who has an unrepaired cleft can get it mended free of charge, or have all expenses covered under the insurance scheme. However, the results of this project show that these programs are not perfect, and that many needy cleft families are still slipping through the cracks.

In light of these findings, it is clear that there are several steps that the Indian government can take to better the lives and increase the acquisition of treatment of its cleft patients. ASHAs need to be better trained, and need to ensure that they reach every child in their designated area and link them to care. Government insurance schemes need to be

improved, and every person who qualifies needs to be made aware of and enrolled in these programs. The Indian education system should be strengthened, and knowledge of basic health issues should be more prioritized. There needs to be a vast expansion of health centers with staff knowledgeable about the diverse needs of cleft patients and capable of delivering the treatment that they require.

### **Project Limitations**

This project had many limitations. Firstly, the sample size for the interviews was very small. Aarohi has treated eight cleft patients at its surgery camps, but only four of them were decided to be accessible to talk with for this study. By then end of the project period, eight interviews were conducted and seven people who were born with clefts were discussed. This fieldwork was unable to draw significant conclusions about the effects of different income or education levels because there were no noticeable trends within the small sample, and the effects of family history and religion could not be determined because only one family had a history of clefts, and all of the families were Hindu. Also, only one cleft patient was present and old enough to speak for herself during the interview. In one of the other cases, the adult patient being discussed was not present, and the remaining patients were younger than 18 years old. It is likely that cleft patients themselves would have given slightly different accounts of their experiences. Furthermore, the sample was biased because only one of the discussed patients had not yet received any cleft care, and four of the patients lived in Aarohi villages and had been identified and treated by them. Therefore, this study could not sufficiently analyze the issues that the people in Nainital district who still are unaware of or unable to access cleft repair face.

Moreover, another limitation in this project was that the responses that people gave during the interviews might have been influenced by a variety of factors. For example, there were many distractions present during each of the interviews with the guardians of the cleft children. Rather than being able to give their undivided attention to the conversation, other factors such as noisy children, neighbors passing by, and attempts at performing chores during the interview, hindered the focus of the respondent, the translator, and the interviewer. Additionally, the respondents knew that the interviewer was associated with Aarohi, so those families who received care from Aarohi may have worded their responses regarding their treatment experiences in a more positive manner than they would have had they not been aware that the interviewer had a connection with the NGO. Furthermore, several of the parents appeared to be slightly apprehensive when asked for their permission to make an audio recording of the conversation. While all of the respondents agreed to this proposition, some of them may not have answered with full and complete honesty due to concerns about how their words would be used.

Also, the fact that the interviewer was a young white American woman with very little knowledge of Hindi could have influenced the responses. Some of the guardians of cleft children made very little eye contact during the interview, and one of the parents said that in his mind, he “treated [the interviewer] like God,” (Guardian IV, Personal Interview). Both the interviewer and the translator were women, which may have impacted the responses in the three conversations with fathers. Concerns about the gender dynamic also had an impact on which questions could and could not be asked. Because there were men present in all of the interviews, the interviewer decided not to ask about if the mother received an antenatal ultrasound, and if so, if the cleft was identified in the womb, and if

this led her to consider abortion. She also did not ask if in hindsight the mother wished that she had known about the cleft and been able to abort the fetus.

As is true whenever a translator is used, there were likely miscommunications between what was being asked and what the response was. Two of the families were more comfortable speaking in Kumaoni than in Hindi. This necessitated the use of two translators, one to translate between English and Hindi, and one to translate between Hindi and Kumaoni. This situation increased the chances of the intended meanings of the interviewer and the participant being altered. In addition, it appeared as though the respondents were sometimes confused by what the interviewer was trying to ask, and rather than not saying anything, gave a response that did not fit with the question.

### **Recommendations for Further Study**

There are several ways in which the present project could be expanded upon in future fieldwork. A larger sample size including families from a wider range of income levels, religions, and education levels could be taken. It would be valuable to be able to find out if there are meaningful differences between people from these different strata, and therefore be able to better know how to reach these people and help them to have comfortable and healthy lives. Similarly, it would be beneficial to study both urban and rural populations in Nainital district and determine how the lives of cleft patients in these two different areas compare and contrast.

In addition, it would be helpful to search for more families who have been informed about cleft treatment options, but who have not pursued care. Being able to fully understand why people in this area who are aware of care do not seek to obtain it would be

worthwhile because it would inform those who provide treatment about what they need to change to make their services more attractive and obtainable. Contact information has been provided below for anyone interesting in working with the Aarohi organization.

Although it would be difficult to execute in an SIT Independent Study Project, work could be done in the future comparing the lives and treatment experiences of people from different states that have differences in their health care and education systems. Knowing what factors have a positive influence on cleft patients and what factors have a negative influence would assist government and NGO staff in planning how to run their programs.

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*Figure 1. Various levels of clefts*

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## **Appendix**

### **Sample Interview Questions for Cleft Patients/Guardians**

Note: the selection and phrasing of specific questions was based on if the participant was the patient, the mother, the father, or another guardian.

- What is your religion?
- Are you married?
- How many children do you have?
- What is your/husbands job?
- How much money do you make?
- Did you go to school? For how many years?
- Did your husband go to school? For how many years?
- Did you learn anything about health while in school?
- What languages do you speak?
- Have you always lived here? If no, where did you live before?
- Where were your children born? Where was this child in particular born?
  
- Did this child have trouble breastfeeding?
- Did they have a cut only in the lip, only in the palate, or both?
- Tell me about the treatment experience...
  - o When did you get treatment?
  - o How old was the child?
  - o Did you try to get treatment anytime before you actually did?
  - o How did your family learn about the treatment?
  - o Where did you go to get it?
  - o How long did it take you to get there?
  - o How did you get there (car, bus, train)?
  - o How far away was it?
  - o How much money did the treatment cost?
  - o How did you get the money (family savings, gift or loan from family or friends, help of NGO or government)?
  - o How long did you stay there?
  - o Did you pay money to stay there? If yes, how much?
  - o Were you concerned about the medicines that the doctors gave the child?
  - o How much time did it take them to recover from the treatment?
  - o Did you go back for more treatment, or did you only go one time?
  - o So, what was the most difficult part about getting treated?
- Are you pleased with the results of the treatment?
- How is your life different since getting the treatment?
- Have you ever wanted or needed more treatment?
  - o Appearance, teeth, speech, hearing problems
  - o If yes, why have you not gotten that treatment?
- Tell me about what your child's life was like before treatment.

- Did they go to school? Play with friends? What were your biggest challenges or concerns?
- Before you got treatment, what did people in your community think or say about the cleft?
  - How did people you did not know react when they saw the cleft?
  - What did your family say about the cleft?
- How has this changed since getting the treatment?
  - What do people say about the scars?
  - Were you worried about finding a husband because of the scars? Did it turn out to be difficult?
- Do you know if anyone in your family has had a cleft?
  - Tell me about that (who, treatment, school, job, marriage, children)
- Have you ever known anyone else who had a cleft? Tell me about it.
- Had you ever seen anyone else with a cleft before you had your child with a cleft?
  - What did you think of that person?
- Why do you think that you were born with a cleft? (eclipse, God's will, punishment from God, lack of certain vitamins while pregnant)
- Have you had any more children after having this child with a cleft? Do you want to?
  - Did you ever think that your next child would have a cleft because this child did?
- Do any of your own children have clefts?
  - Did you ever think that your children would have clefts because you had a cleft?
- Do you think that your life would have been different if... (If yes, in what ways?)
  - Had more money
  - Lived closer to a hospital
  - Had more education about health
- Have you ever known anyone with a different kind of deformity?
  - Tell me about it (is having that deformity better or worse than having a cleft, and why?)
- Is there anything else that you would like to tell me?
- Are there any people that you think that I should talk to about this topic?