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Research Article

Physical Impairments, Psychological Impact, and Risk Factors of Cleft Lip and Palate in Children from a Surgical Mission Project in Armenia, Colombia

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Abstract

Objective:

1. To learn the incidence and the types of perceived physical and psychological problems in children and adolescents with cleft lip (CL) and cleft palate (CP) in rural Colombia
2. To learn the risk factors in mothers of CL and CP children

Design: The study was prospective and descriptive in nature. All the eligible patients and families were given a survey to evaluate demographics as well as physical and psychological issues. The survey was a written questionnaire. A local translator was present on site to help with survey questions.

Setting: The project was conducted in the rural underserved area of Armenia, Columbia in January 2014. Cliníca de la Sagrada Familia in Armenia supported the project.

Patients and Participants: Patients who were pre-selected to undergo surgery were given surveys. They answered questions by themselves, as much they were able to. Mothers provided answers for questions that patients could not answer. In cases where patients were too young, the mothers answered the entire survey for the patient. However, mothers answered specific questions pertaining to their demographics and risk factors.

Main Outcome Measures: The incidence of perceived physical and psychological impairments in patients and risk factors in mothers in Armenia, Columbia were reported.

Results: A total of 24 surveys were completed by patients and in some cases their families, when the patient was too young. The median age among children and adolescents was 17 years. The reported physical defects included problems with swallowing (42%), speaking (32%), dental (32%), and breathing (26%). The psychological problems reported included bullying (50%), depression (33%), and poor school performance (33%). However, the psychological impact reported was greater in patients above 24 years of age.

Conclusions: Children, adolescents, and adults reported both physical and psychological issues from cleft lip and cleft palate. We believe it is imperative that patients receive a thorough assessment of both their perceived physical and psychological issues at a young age.

Risk factors included genetic inheritance, possibly diabetic mothers, possible exposure to chemicals such as various fertilizers, and possibly pregnancy of mothers at a young age. However, a study involving a larger population is required.

Keywords: *Physical Impairments; Psychological Impact; Cleft Lip; Cleft Palate*

Introduction

Cleft Lip and cleft palate are birth defects that occur from early pregnancy and include incomplete fusion of lip or palate or both. Every year in the United States, 4437 babies are born with cleft lip with or without cleft palate, and 2651 babies are born with solely cleft palate. Isolated CL or CP is more common [1]. About 70% of cases are non-syndromic and do not have other birth defects associated with it [2]. There are racial and ethnic risks for oral clefts. Asians have the highest risk with 14 in 10,000 cases followed by whites with 10 in 10,000 cases and blacks with 4 in 10,000 cases [3]. Among East Asians, Southeast Asians, Japanese, Korean, Chinese, and Filipinos have the highest number of incidences of the pacific islanders [4]. Amerindians among South Americans have the highest incidence [5,6].

CL and CP can result in both physical and psychological problems. They include speech defects, feeding problems, ear infections, hearing problems, and dental problems. Some of the psychological problems include anxiety, depression, low self-esteem, feelings of isolation, and poor performance in schools and colleges. Additionally, bullying was reported as a common problem among the patients [7,8].

Methods

The operation San Jose mission project was funded and organized by The CHRISTUS Foundation for HealthCare. A group of plastic surgeons, anesthetists, a pediatrician, nurses, a speech therapist, a nutritionist, and volunteers from Houston participated in the project from January 17-26, 2014. The medical group in Armenia screened patients for the project. After obtaining their consent, all of the families were given a survey in Spanish to evaluate demographics as well as physical and psychological issues before the corrective surgery. A local translator was on site to help with questions. Some patients filled out the written survey by themselves while others preferred to transmit their answers orally. Simple statistical formulas were used to find the frequencies, percentages, mean, and median.

Results

A total of 24 surveys were completed with 19 patients (79%) under 24 years of age and 5 (21%) above 24 years. The response was categorized into demographics and risk factors (Table 1), physical impairments (Figure 1), and psychological impact (Figure 2). A majority of the patients were children and adolescents less than 24 years of age, with 63% males and 37% females. The median age among children and adolescents was 17 years, ranging from 7 months to 24 years. Most were attending school, and were of low-income parents. 58 % of mothers were 35 years of age or above. The majority of children patients under 24 years had combined defects of CL and CP (60%). The physical impairments reported included swallowing (42%), speech (32%), dental (32%), and breathing (26%). The other issues, which were not as highly recorded, included problems with hearing, infection, and nutrition. The perceived psychological problems reported of patients less than 24 years of age included depression (28%), perceived poor school performance (33%), self-image (22%), self-confidence (17%), and isolation (22%). The common issue of bullying was reported by 50 % of the patients (Figure 1 and 2).

	Less than 24 years of age	More than 24 years of age
Number (%)	19 (79%)	5 (21%)
Age	Range-7months-24 years Median-17 years	Range-29 yrs-52 years Median-42
Gender	Males-12 (63%), Females-7 (37%)	Males-2 (40%) Females-3 (60%)
Grade	Elementary-6 (31.5%) Middle School-6 (31.5%) High School-4 (21%) College-3 (16%)	Elementary-0 Middle School-1 (20 %), High School-4 (80%) College-0
Type of Deformity	Cleft Lip-3 (15%) Cleft Lip/Cleft Palate-12 (60%) Bil Cleft Lip/Cleft Palate-1 (5%) Cleft Palate & Deviated Nasal Septum-1 (5%) Bil Cleft Palate-1 (5%) Follow up only-1 (5%)	Cleft Lip/Cleft Palate- 4(80%) Cleft Lip/Cleft palate/Nose-1 (20%)
Mother's Age	15-19yrs-1(5%) 20-29yrs-6 (32%) 30-39yrs-4 (21%) (> 35yrs-1) 40-49yrs-4 (21%) 50-55yrs-4 (21%)	15-19yrs-0 20-29yrs-2 (40%) 30-39yrs-2 (40%) (> 35-2) 40-49yrs-1 (20%) 50-55yrs-0
Relatives with defect	Yes-8 (42%) No-11 (58%)	Yes-1 (20%) No-4 (80%)
Diabetes in mother	Yes-4 (21%) No-15 (79%)	Yes-4 (80%) No-1 (20%)
Smoking in mother	Yes-1 (5%) No-18 (95%)	Yes-0 No-5 (100%)
Alcohol in mother	Yes-1 (5%) No-18 (95%)	Yes-0 No-5 (100%)
Exposure to Chemicals	Yes-8 (42%) No-11 (58%)	Yes-2 (40%) No-3 (60%)

Table 1: *Demographics.*

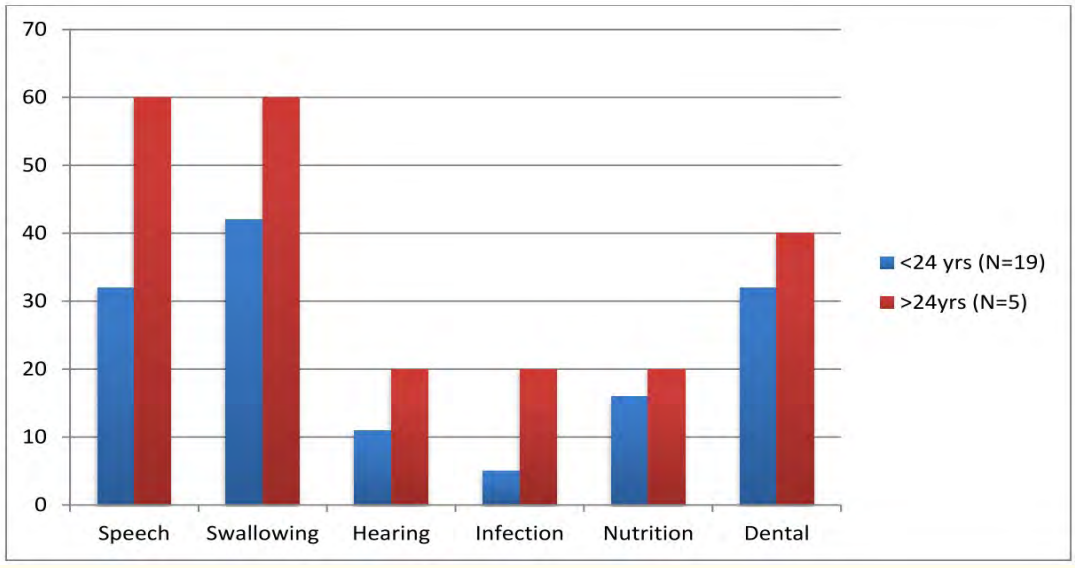

Figure 1: *Physical Impairments in Cleft Lip and Cleft Palate.*

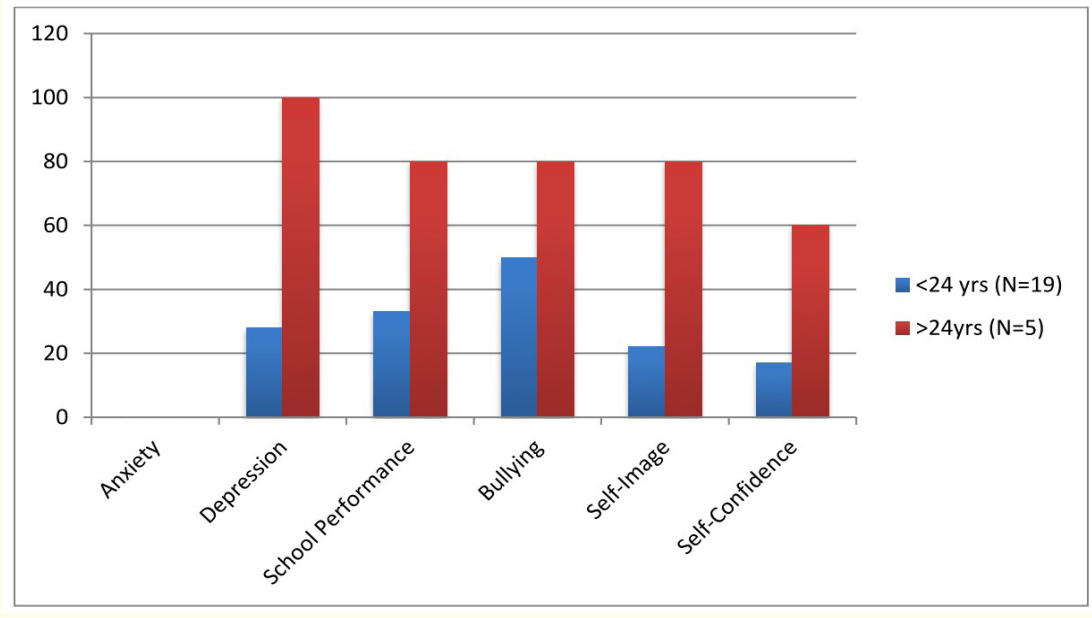

Figure 2: *Psychological Impact of Cleft Lip and Cleft Palate.*

The perceived physical impairments in patients above 24 years of age were speaking problems (60%), swallowing difficulties (60 %), breathing difficulties (60%), and dental issues (40 %). In addition, they had issues with hearing, infection, and nutrition, all of which were 20%.

The perceived psychological issues noted in this age group were depression (100%), poor school performance (80%), self-image (80%), self-confidence (60%), and isolation (80%). Surprisingly, none of the patients in any age group reported anxiety. Bullying was noted to be very high in 80% of the patients. Risk factors included possible genetic inheritance, diabetic mothers, possible exposure to chemicals, and potentially pregnancy of mothers at a young age. Tobacco smoking and alcohol use in mothers with affected children during pregnancy were not significant.

Discussion

The psychological impact in children and adults born with this defect has not been studied well in Latin America. We noted perceived physical impairments, but the high incidence of perceived psychological issues was surprising. Our survey indicated that bullying in schools is rampant and probably promotes low self-esteem and shows poor performance in school.

Congenital clefts produce devastating physical and psychological impairments in children. These generally improve with surgical interventions. Our study also confirmed perceived physical defects in swallowing, speech, breathing, and dental issues [9]. In addition, psychological impairments are described and documented in a number of studies across different countries. Psychological problems are not well studied in rural South America. In our small qualitative study, the perceived psychosocial problems were experienced by children, adolescents, and adults, but are more pronounced in adults. Our study was done preoperatively in patients who were undergoing surgery for the first time, but the majority was undergoing revision of previous surgeries. Our qualitative study was an attempt to capture psychological effects of these defects in adolescents and adults undergoing surgery. We discovered that perceived psychological problems are common and include depression, poor performance in school, and issues with self-image, self-confidence, and isolation. But the most common reported issue was bullying among this population. These issues have a major impact both on the patient and their families. Avinash De Souza., *et al*. [10] emphasized the need to do preoperative evaluation of psychological issues in patients with clefts. They suggested that psychological evaluation pre-operatively maximizes positive outcome of surgery and rehabilitation. They outline the need to improve methodologies in doing such research. There is evidence that these psychological effects persist even after corrective surgery. Pillemer FG, Cook KV [11] noted that psychological issues after corrective surgery included low self-esteem, impaired peer relationships, and greater dependency on significant adults. They found that positive psychological adjustment was related to greater physical attractiveness, lower parental stress, and younger age. They concluded that children having craniofacial surgery should have supportive psychotherapeutic services.

Turner., *et al*. [12] studied psychological outcomes of cleft patients among patients and families. Upon interviewing 112 patients and 130 parents in nine hospitals, it was found that 73 % of 15 - 20 year old patients felt their self-confidence was affected by cleft abnormality, and 60% were teased about their speech and cleft related abnormalities. Seven families were referred for psychological counseling for emotional support after this study. For the most part psychosocial aspects of CL and CP are neglected and overlooked in these patients and families. Our study revealed that the incidence of low self-confidence was very high in adults, but lower in adolescents. This may be due to the fact that adults were more exposed to society and sought higher education in college. This also might have been due to a buildup of self-confidence issues over the years. This low self-esteem and low self-confidence may be due to a number of causes. Self-perception plays a role in self-esteem and psychological adjustment among children. Parental influence can play a role in changing self-perception among kids. Parents may be more tolerant of misbehavior due to over-protection [7]. The perception of the general population and their biases towards these deformities may be another reason for low self-esteem and other psychological issues. Rankin and Borah [13] in

their study compared digitally altered photographs of patients with facial abnormalities of identical patients. They discovered that photographs with abnormal facial problems that were presented to a population came with the notion that the patients with abnormal faces were less trustworthy, less honest, less employable, less capable, less effective, less optimistic, less intelligent, less popular, and less attractive. Negative perceptions of patients with facial deformities occur regardless of sex, educational level, and age of evaluator.

Bullying and teasing by peers is common [8]. In our study, bullying was the most commonly reported issue. It was reported by 50% below 24 years of age and 80% in patients above 24 years of age. These psychological issues are well carried into adult life. This probably behooves us to do a thorough psychological evaluation and offer them counseling on a long-term basis to regain confidence, self-image issues and improve performance in school and colleges.

Communication issues start at an early age leading to language disorders and thus, to behavioral inhibition and low school performance [14]. In our study, patients noted speech difficulties in 32% of adolescents and in 60% of adults. Speech difficulties are due to both perceived physical and psychological issues that influence the development of a child.

Other important psychological issues that need attention and treatment include anxiety and depression. The occurrence of anxiety and depression reported by Remsted to be twice as much as in normal control group adults [14]. It is also reported that parents with same deformity may experience mental crisis due to their own experience [15,16]. These issues are not well documented among South American populations. Our study revealed that depression reported in 28% of adolescents and 100% of adults. However, none of the patients reported any anxiety. This could have been possibly due to the lack of clear understanding of the term anxiety.

The risk factors in mothers were discussed in a number of studies. In a study by Shah, these defects show correlation between mother's age and the defect [17]. Other studies failed to show age as a risk factor [18]. Our findings indicate that a mother's age may play a determining role. About 40% of these defects in adolescents were noted when their mothers were above 40 years of age at the time of their birth. This phenomenon was not significant in older patients above 24 years of age.

It is reported that cleft defects are reported to run in families and are passed on from parents to children. A study by Natsume., *et al.* demonstrated that cleft defects are more common with a family history of clefts [19]. Our survey revealed close relatives with the same defect accounted for 42% in adolescents were not significant in other groups.

The association of diabetes as a risk factor is well documented. Diabetes was recorded in 21% of adolescents compared to 80% of older patients in our study. In a study by Corea, diabetes was identified as a risk factor in mothers during pregnancy [20]. Another risk factor studied previously was chemical exposure and pollution in industrial towns with unregulated factories. In a study by Shah et al pesticides was identified as a risk factor for orofacial clefts and neural tube defects [21]. In our survey mothers reported exposure to chemicals in 42% of adolescents group and 40% of adults patients. We did not confirm if the pollution was worse in the area where patients lived. However, our population was rural, and agriculture was the main occupation of the people.

Folic acid deficiency and prescription drug intake during pregnancy like anti-epileptic drugs such as topiramate or valproic acid are other risk factors reported by some studies [22]. Smoking was reported in some studies as a risk factor [23,24]. Our study failed to show smoking and alcohol as risk factors. It was difficult to find out if mothers attended prenatal clinics and took folic acid as routine.

Our study did identify a number of risk factors as reported by mothers. But the numbers were small to conclude that any of these risk factors in mothers contributed to CL and CP. This was beyond the scope of our study. One needs to conduct a larger study to identify these factors at future camps.

Conclusion

Children, adolescents, and adults experience a multitude of perceived physical and psychological symptoms from cleft lip and cleft palate. We believe it is imperative that patients receive a thorough assessment for both physical and psychological issues at an earlier age. They need support and psychotherapy on a long-term basis to regain their self-image and confidence. We recommend that psychological assessment should become a routine practice for these patients and also be incorporated in future research. Risk factors in mothers should be identified and prevented in the future through education and counseling about diet, risks of alcoholism, diabetes, and consanguineous marriages.

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