

Family Environment of Individuals With Oral Clefts in Argentina

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Objective: The purpose of this investigation was to study the social environment of families of children with different types of nonsyndromic oral clefts (OC) and to compare these groups with a control population of families of children without clefts.

Design: The study compared three nonsyndromic oral cleft groups and the control group using the Moos Family Environment Scale, which examines cohesion, expressiveness, conflict, independence, achievement-orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization, and control.

Setting: All parents of children with nonsyndromic oral clefts from a large craniofacial clinic in Buenos Aires, Argentina, were identified and were enrolled in this study between June 2000 and August 2001. Control families were ascertained from the pediatrics service of a hospital located in the vicinity of the craniofacial clinic.

Participants: One hundred and sixty-five parents were selected, based on having a child with nonsyndromic unilateral cleft lip with or without cleft palate (UCL/P), bilateral cleft lip with or without cleft palate (BCL/P), or isolated cleft palate (ICP). One hundred and eighty control parents with no family history of congenital anomalies were selected, as well.

Results: There was no major difference in the social environment of families of children with different types of nonsyndromic oral clefts. When compared with families in the control group, families of children with nonsyndromic oral clefts scored better in all three subdimensions of family relationship, revealed a high level of independence, and showed better structure and organization than control families did; however, families of children with nonsyndromic oral clefts reported participating in fewer recreational activities.

Conclusions: Overall, families of children with nonsyndromic oral clefts displayed a good social environment. Efforts should be focused to involve them in recreational activities.

KEY WORDS: *cleft lip and palate, family environment scale, psychology, stigma, stress*

Pediatric chronic physical disorders, such as oral clefts (OC) and their associated complications, rarely affect only the child. Because mothers typically carry the majority of the burden for the daily care of these children, particular concern is raised for the mothers' adaptation (Wallander et al., 1989). During the

last decade, a large body of research focused on the processes that lead to family adaptation in accepting a child with a craniofacial anomaly (see reviews by Endriga and Kapp-Simon, 1999, and Broder, 2001). Several authors have referred to identifiable phases that families undergo as a result of their child's OC, similar to the stages identified in the bereavement literature. For parents of a child with an OC, these include initial shock and disbelief, often followed by rage, guilt, denial, and adjustment or acceptance (Kapp-Simon, 2002).

Family functioning has received increasing empirical attention as a potential mediator of psychological adaptation to pediatric chronic disorders (Varni et al., 1988). Moos et al. (1990) described a conceptual framework in which family environment and family members' adaptation mutually influence each other, as shown in Figure 1. More specifically, each adult family member's personal characteristics, coping skills, and

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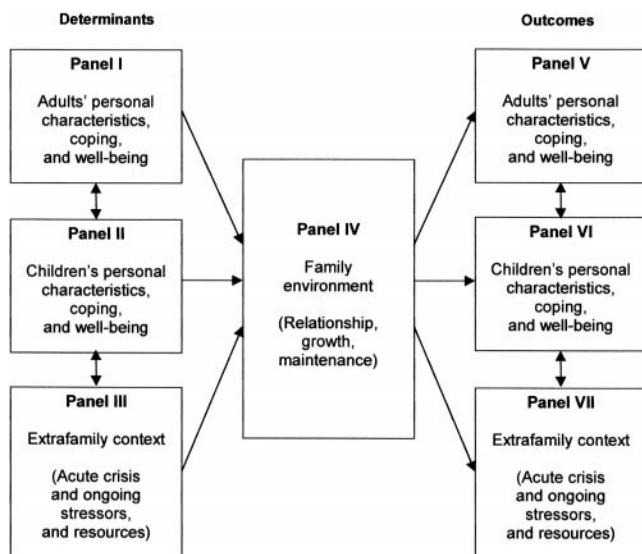


FIGURE 1 Conceptual model of the determinants and outcomes of the family environment. (Reproduced by special permission of the Publisher, Mind Garden, Inc., 1690 Woodside Road #202, Redwood City, CA 94061 USA www.mindgarden.com from the Family Environment Scale by Rudolf H. Moos. Copyright 1974, 2002 by Rudolf Moos. All rights reserved. Further reproduction is prohibited without the Publisher's written consent.)

well-being (Panel I) can affect the quality of family relationship, the family's emphasis on personal growth goals, and the family's focus on system maintenance (Panel IV). Family climate is also influenced by the children's personal characteristics, coping skills, and well-being (Panel II), and acute life crises and ongoing stressors, as well as resources from settings outside the family, such as school and work (Panel III). For example, aspects of the mother's and father's workplaces or a child's experiences at school can affect the family climate. Moreover, when a life crisis occurs, such as the birth of a child with an OC, other family members' personality characteristics and coping skills can alter the influence of the crisis on the family. The family environment might also provide a protective influence, reducing the stressors and enhancing social resources associated with extrafamily-life context factors (Panel VII). For example, a child with an OC whose family is outgoing and accepting of people's differences might be less stressed about meeting other children.

Little is known about the family environment of children with OC living in developing nations. In addition to the stressors found in developed countries, families living in developing nations are often faced with political and financial instability, corruption at various levels, and fear of physical harm. In the present study, parents of 169 patients with nonsyndromic oral clefts from a large craniofacial center in the suburbs of Buenos Aires, Argentina, and parents of 180 children who attended a regular checkup pediatric appointment in a general hospital in the suburbs of Buenos Aires were administered a questionnaire that included socio-demographic questions and measures of perceived family environment. The aims of this study were to describe how parents of children with OC perceive their family climate, to test whether having a child with a certain OC is

associated with specific family characteristics, and to compare the environment of families of children with OC with that of a sample of families of children without congenital anomalies.

SAMPLE AND METHODS

Sample

The Asociación Piel is a large outpatient craniofacial clinic in Avellaneda, an industrial suburb of the city of Buenos Aires. It provides multidisciplinary assessment and treatment services, including plastic surgery, pediatrics, dentistry, speech-language pathology, and genetic counseling to 141 new patients and 482 follow-up patients with craniofacial conditions per year. The study sample consisted of 165 parents of children with nonsyndromic OC who were treated at Asociación Piel between June 2000 and August 2001 and who agreed to answer the questionnaire at one of the clinic visits (Wyszynski et al., 2003). Sixty-three percent of the respondents were mothers, 27.8% were fathers, and approximately 9% were other family members. Seventy-two percent of respondents resided in the province of Buenos Aires (the suburbs of the capital city), whereas about 17% were from the capital city of Buenos Aires. A trained study researcher was always available nearby to answer any questions with regards to the questionnaire. As part of the informed consent process, all participants were encouraged to answer the questions as truthfully as possible. The local Ethics Committee approved the study.

Controls

The control sample consisted of 180 parents of children who attended a scheduled checkup pediatric visit at the Hospital Zonal Dr. Carlos A. Bocalandro between January 2003 and June 2003. This hospital is free and public, is supervised by the Ministry of Public Health of the Province of Buenos Aires, and is located in the vicinity of Asociación Piel. Eighty-eight percent of the respondents were mothers and the remaining 12% were fathers. Forty-three percent of respondents resided in the province of Buenos Aires, whereas 56% were from the capital city of Buenos Aires. No child, spouse, or relative of the control parents had a known congenital anomaly.

Measurement

The survey used a semistructured format and combined open-ended, multiple-choice, and yes/no questions. It included 61 questions pertaining to demographics, religious beliefs, type of cleft the child has, perception of severity of the cleft, satisfaction with various medical treatments, and reproductive choice (see Wyszynski et al. [2003] for a study on attitudes toward prenatal diagnosis, termination of pregnancy, and reproduction by these parents). The Moos Family Environment Scale (FES; Moos and Moos, 1994) was used to elicit information from case and control parents about the social environment in the home and family. This is a true/false instrument

with 90 items that yields 10 subscales: cohesion, expressiveness, conflict, independence, achievement-orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization, and control. The psychometric characteristics of the FES are adequate (Plomin and DeFries, 1985; Moos and Moos, 1994), and the scale has been used with increasing frequency in research on the relationship of family environment and psychiatric disorders in children and adults (Breslau, 1990).

Definition of Scales and Subscales

Relationship Scale

Cohesion, expressiveness, and conflict assess how involved people are in their families and how openly they express both positive and negative feelings.

The cohesion subscale measures the degree of commitment, help, and support family members provide one another, for example: the way they support one another, the amount of energy they put into what they do at home, and how much feeling of togetherness there is in the family.

The expressiveness subscale taps the extent to which family members are encouraged to act openly and to express their feelings directly; for example: how openly family members talk around home, how freely they discuss their personal problems, and how often they just pick up and go if they feel like doing something on the spur of the moment.

The conflict subscale measures the amount of openly expressed anger, aggression, and conflict that exists among family members; for example: the frequency of fights, whether they sometimes get so angry that they throw things, and how often they criticize each other.

Personal Growth Subscales

These focus on the family's goals by tapping the major ways in which a family encourages or inhibits personal growth. The Personal Growth Dimensions include the independence, achievement-orientation, intellectual-cultural orientation, active-recreational orientation, and moral-religious emphasis subscales.

The independence subscale measures the extent to which family members are assertive, are self-sufficient, and make their own decisions; for example: how strongly family members are encouraged to be independent, how much they think things out for themselves, and how freely they come and go in the family.

The achievement-orientation subscale taps the extent to which activities, such as school and work, are cast into an achievement-oriented or competitive framework; for example: how important they feel it is to do their best and to get ahead, and how much they believe in competition and "may the best man win."

The intellectual-cultural orientation subscale assesses the degree of interest in political, social, intellectual, and cultural

activities; for example: how often family members talk about political or social problems, how often they go to the library, and how much they like music, art, and literature.

The active-recreational orientation subscale taps the extent of participation in social and recreational activities; for example: how often friends come over for dinner or to visit, how often family members go out, and how often family members go to movies, sports events, or camping.

The moral-religious emphasis subscale measures the degree of emphasis on ethical and religious issues and values; for example: how frequently family members attend church, synagogue, or Sunday School; how strict their ideas are about what is right and wrong; and how much they believe there are some things that just must be taken on faith.

System Maintenance Dimensions

These assess the family's emphasis on clear organization, structure, rules, and procedures in running family life. There are two subscales in this set: organization and control.

The organization subscale measures the importance of clear organization and structure in planning family activities and responsibilities; for example: how carefully activities are planned, how neat and orderly family members are, and how clearly each person's duties are defined.

The control subscale assesses the extent to which set rules and procedures are used to run family life; for example: how often one family member makes the decisions, how set the ways of doing things are at home, and how much emphasis is placed on following rules in the family.

Pilot Study

The survey was developed and administered for pilot testing to 10 mothers of children with OC. This was particularly important given that the FES was translated and adapted to Spanish and that, to the best of the authors' knowledge, this survey had not been used in Argentina before. Questions that were thought to be confusing or ambiguous were modified as needed.

Statistical Analysis

Three groups were compared with each other: unilateral cleft lip with or without cleft palate (UCL/P, $n = 80$), bilateral cleft lip with or without cleft palate (BCL/P, $n = 69$), and isolated cleft palate (ICP, $n = 16$). The combination of these three groups (Total) was also compared with the 180 controls. Statistical analyses were carried out with the software program Stata, version 7.0 (Stata Corp., College Station, TX). For continuous data, means and standard deviations were calculated and potential differences were tested with simple linear regression. In the case of ordinal variables, a multiple logistic regression was used to obtain odds ratios (ORs) and their 95% confidence intervals (CIs), and to derive adjusted p values.

TABLE 1 Characteristics of Respondents to the Family Environment Scale by Type of Oral Cleft† and Controls‡

Characteristic	UCL/P (n = 80)	BCL/P (n = 69)	ICP (n = 16)	Total (n = 165)	Controls (n = 180)
Respondent's age (mean, SD)	34.1 (7.7)**	38.8 (10.9)**	35.7 (7.3)	36.1 (9.5)	29.4 (9.2)***
Child's age (mean, SD)	6.0 (4.2)	6.9 (4.3)	5.5 (3.8)	6.4 (4.8)	—
Female respondent	55 (68.8)	45 (65.2)	12 (80.0)	112 (68.3)	158 (88.8)***
Area of residence					
Rural	—	1 (1.5)	—	1 (0.6)	4 (2.3)
Small city/town	45 (57.0)	22 (31.9)	6 (40.0)	73 (44.8)	59 (33.5)
Major metropolitan area	34 (43.0)	46 (66.7)	9 (60.0)	89 (54.6)	113 (64.2)
Marital status					
Single/Never been married	9 (11.3)	8 (11.9)	3 (18.8)	20 (12.3)	78 (43.8)***
Married	68 (81.3)	48 (71.6)	11 (68.8)	124 (76.1)	73 (41.0)***
Divorced/Separated	4 (5.1)	9 (13.5)	2 (12.5)	15 (9.2)	25 (14.4)
Widowed	2 (2.5)	2 (3.0)	—	4 (2.5)	2 (1.1)
Ethnicity					
Aborigine	12 (15.8)	5 (7.9)	3 (18.8)	20 (12.9)	22 (13.4)
White/Caucasian	12 (15.8)	20 (31.8)*	2 (12.5)	34 (21.9)	69 (42.1)
Hispanic/Latino	52 (68.4)	38 (60.3)	11 (68.8)	101 (65.2)	73 (44.5)
Employment					
Full-time	24 (32.4)	24 (36.4)	2 (13.3)	50 (32.3)	12 (6.8)***
Part-time	29 (39.1)	16 (24.2)	5 (33.3)	50 (32.3)	40 (22.7)***
Unemployed	12 (16.2)	9 (13.6)	5 (33.3)	26 (16.8)	97 (55.1)***
Retired	—	1 (1.5)	—	1 (0.7)	2 (1.1)
Highest school level achieved					
Less than high school	17 (21.3)	23 (33.8)	6 (37.5)	46 (28.1)	122 (67.8)***
High school diploma	29 (36.3)*	15 (22.06)	5 (31.3)	49 (29.9)	34 (18.9)***
Some college or technical school	8 (10.0)	8 (11.8)	2 (12.5)	18 (11.0)	8 (4.4)***
College diploma	13 (16.3)	8 (11.8)	2 (12.5)	23 (14.0)	4 (2.2)***
Some graduate school	5 (6.3)	7 (10.3)	—	12 (7.3)	10 (5.6)*
Graduate diploma	8 (10.0)	7 (10.3)	1 (6.3)	16 (9.8)	2 (1.1)
Christian Catholic religion	76 (95.0)	57 (82.6)	16 (100.0)	149 (90.3)	112 (62.2)***

† UCL/P = unilateral cleft lip with or without cleft palate; BCL/P = bilateral cleft lip with or without cleft palate; ICP = isolated cleft palate.

‡ Percentages do not sum to 100 because of missing values: * $p < .05$; ** $p < .01$; *** $p < .001$. Comparisons were carried out between one of the oral cleft groups and the combination of the other two, as well as between "Total" and controls, using simple linear or logistic regression.

RESULTS

Table 1 presents demographic characteristics of the populations under study. The regression analyses of each oral cleft group compared with the other two revealed that all respondents had very similar characteristics. The parent respondents in the UCL/P group were younger ($p = .005$) and had a higher proportion of high school graduates ($p = .038$) than the other two groups, whereas parent respondents in the BCL/P group were older ($p = .003$) and included more Whites/Caucasians ($p = .046$) than the other two cleft groups. When compared with the combined group of case parent respondents, controls were younger (29.4 versus 36.1 years of age, $p < .001$), predominantly women (88.8% versus 68.3%, $p < .001$), and more frequently single (43.8% versus 12.3%, $p < .001$). More than half of the controls were unemployed (controls: 55.1% versus cases: 16.8%, $p < .001$) and a high proportion had an education level lower than high school diploma (controls: 67.8% versus cases: 28.1%, $p < .001$). Finally, controls were less frequently Christian Catholic than cases (62.2% versus 90.3%, $p < .001$).

Table 2 shows the means and standard deviations of all 10 subscales for each of the three groups and the controls. Simple logistic regression adjusting for mother's age revealed no sta-

tistically significant difference among the three OC groups. When the total cleft population was compared with the controls, four subscales were higher in the cases and two in the controls. Four subscales (achievement-orientation, intellectual-cultural orientation, moral-religious emphasis, and control) did not differ. The multiple logistic regression analysis, which simultaneously adjusted for respondent's age, sex, and level of schooling, revealed that families of children with OC score better in all three subdimensions of family relationship, have more independence, and show better structure and organization than controls; however, they report participating in fewer recreational activities.

In order to better understand behaviors and perceptions of children with OC and their family members, survey respondents were asked 10 additional questions. Table 3 presents the ORs and 95% CIs for these questions, as they were answered by each group compared with the other two. Between 11% and 20% of all the children seemed to have had school problems because of their appearance; however, there was no difference when the groups were compared with each other. Almost half of the relatives of children with ICP (42.9%) noted that the child's ability to make friends was affected by the oral cleft. This percentage was significantly higher than that found in the other two groups (OR: 7.45, 95% CI: 2.17 to 25.55).

TABLE 2 Social Environment of Families of Patients with Oral Clefts* and Controls as Measured by the Family Environment Scale (Mean and Standard Deviation)†

<i>Dimensions</i>	<i>UCL/P</i> (<i>n</i> = 80)	<i>BCL/P</i> (<i>n</i> = 69)	<i>ICP</i> (<i>n</i> = 16)	<i>Total</i> (<i>n</i> = 165)	<i>Controls</i> (<i>n</i> = 180)	<i>Total Versus Controls</i> (<i>Adjusted p Value</i>)*
Relationship						
Cohesion	7.90 (1.17)	8.12 (1.00)	8.00 (0.97)	8.01 (1.05)	7.11 (1.52)	<.001
Expressiveness	6.02 (1.50)	6.42 (1.23)	6.14 (1.35)	6.22 (1.36)	5.74 (1.52)	.008
Conflict	1.98 (1.11)	1.78 (1.46)	2.27 (1.91)	1.91 (1.38)	3.02 (1.51)	<.001
Personal growth						
Independence	6.44 (1.37)	6.68 (1.18)	6.64 (1.39)	6.57 (1.29)	5.31 (1.32)	<.001
Achievement-orientation	5.14 (1.32)	5.02 (1.32)	5.19 (1.28)	5.09 (1.31)	5.23 (1.27)	.151
Intellectual-cultural orientation	5.37 (1.54)	5.11 (1.74)	5.00 (2.00)	5.21 (1.68)	4.26 (1.64)	.167
Active-recreational orientation	4.07 (1.91)	4.29 (1.72)	3.50 (1.59)	4.11 (1.80)	4.40 (1.74)	.007
Moral-religious emphasis	5.73 (1.72)	5.87 (1.77)	4.8 (1.21)	5.69 (1.71)	5.66 (1.27)	.884
System maintenance						
Organization	6.94 (1.59)	7.38 (1.56)	7.33 (0.98)	7.19 (1.53)	6.25 (1.80)	<.001
Control	3.90 (1.60)	4.13 (1.56)	4.50 (1.70)	4.15 (1.60)	3.86 (1.56)	.530

* *p* values were adjusted for respondent's age, sex, and level of schooling using multiple logistic regression.

† UCL/P = unilateral cleft lip with or without cleft palate; BCL/P = bilateral cleft lip with or without cleft palate; ICP = isolated cleft palate.

TABLE 3 Odds Ratios (and 95% Confidence Intervals) for Psychological and Social Responses of Families of Children With Oral Clefts*†

	<i>UCL/P</i> (<i>n</i> = 80)	<i>BCL/P</i> (<i>n</i> = 69)	<i>ICP</i> (<i>n</i> = 16)
Do you think your affected child has had problems in school because of his/her appearance?			
Yes	0.55 (0.22 to 1.40)	1.33 (0.53 to 3.37)	2.58 (0.59 to 11.22)
In your opinion, has your child's condition affected his/her ability to make friends?			
Yes	0.27 (0.09 to 0.81)	1.21 (0.45 to 3.24)	7.45 (2.17 to 25.55)
Has your child with cleft lip/palate made any comments about being called names at school or elsewhere in connection with the cleft lip/palate?			
Yes	0.57 (0.25 to 1.30)	1.63 (0.72 to 3.70)	1.32 (0.32 to 5.44)
Did you ever avoid taking your affected child with you to social gatherings or public places?			
Yes	1.50 (0.53 to 4.25)	1.05 (0.37 to 3.00)	—
Did you ever avoid having pictures taken of your affected child or avoid showing the pictures to others?			
Yes	5.25 (1.67 to 16.49)	0.30 (0.10 to 0.94)	—
People have a range of attitudes about various traits/conditions. With trait (such as hair color or eye color) on one end of the spectrum and disorder on the other, where, in your opinion, does the cleft of your child fall?			
Median (mean, SD)	2 (3.12, 2.6)	3 (3.24, 2.1)	3 (4.00, 2.8)
If you had to choose one word, which of the following would best describe the cleft lip/palate of your child?			
Trait	Baseline	Baseline	—
Difference	0.70 (0.28 to 1.75)	0.78 (0.31 to 2.01)	—
Condition	0.38 (0.10 to 1.39)	1.33 (0.38 to 4.65)	—
Disability	0.75 (0.04 to 12.61)	—	—
Disorder	0.44 (0.20 to 0.98)	1.33 (0.61 to 2.91)	—
Disease	1.88 (0.33 to 10.5)	—	—
The following statement best reflects your view about your child's cleft lip/palate:			
Your child's cleft is a serious condition	0.51 (0.26 to 1.00)	1.18 (0.60 to 2.31)	3.60 (1.23 to 10.56)
To what extent do you agree or disagree that your child has advantages that come with having a cleft lip/palate:			
Strongly agree	1.58 (0.40 to 6.21)	0.97 (0.25 to 3.82)	—
Somewhat agree	0.46 (0.14 to 1.53)	1.06 (0.36 to 3.14)	3.07 (0.83 to 11.32)
Somewhat disagree	3.36 (1.21 to 9.28)	0.45 (0.16 to 1.25)	—
Strongly disagree	Baseline	Baseline	Baseline
To what extent do you agree or disagree that your child has disadvantages that come with having a cleft lip/palate:			
Strongly agree	0.51 (0.16 to 1.59)	0.74 (0.24 to 2.24)	5.30 (1.38 to 20.38)
Somewhat agree	1.11 (0.49 to 2.50)	0.98 (0.43 to 2.20)	0.73 (0.14 to 3.81)
Somewhat disagree	2.67 (0.86 to 8.31)	0.51 (0.17 to 1.60)	—
Strongly disagree	Baseline	Baseline	Baseline

* UCL/P = unilateral cleft lip with or without cleft palate; BCL/P = bilateral cleft lip with or without cleft palate; ICP = isolated cleft palate.

† The "—" sign was used when there was not sufficient sample size to carry out the statistical analysis.

About 20% of the children in each of the three groups admitted they were being called names at school (or elsewhere) in connection to their cleft. Avoiding taking the child with a cleft to a social gathering or public place was mentioned by almost 10% of the relatives of children with UCL/P and BCL/P; however, this behavior was not mentioned by any relative of children with ICP (a similar pattern was observed when relatives were asked whether they ever avoided having pictures taken of their affected child or whether they avoided showing the pictures to others). On a Likert scale from 1 (trait) to 10 (disorder), most participants classified the oral cleft of their children between 2 and 3. This is consistent with their responses to the next question, which asked them to choose one word that would best describe the cleft lip/palate of their children. Most relatives of children with cleft lip chose the term *trait* (UCL/P: 43.8%, BCL/P: 36.4%), whereas 40% in the ICP group selected the word *disorder*. Despite the perception that the cleft of their children is closer to a trait than to a disorder, 27% of relatives of children with UCL/P, 37.1% of children with BCL/P, and 62.5% of children with ICP believe their children's cleft is a serious condition. Finally, the vast majority of the participants did not use the OC as a reason to attribute advantages or disadvantages to their children.

DISCUSSION

The results of the present study indicated that there was no major difference in the social environment of families of children with UCL/P, BCL/P, and ICP. When compared with a control population of families with children without OC, however, several differences became apparent. First, families of children with OC scored better on all three subdimensions of family relationship, showing good cohesion, low level of conflict, and above-average expressiveness. This finding is in agreement with other studies that showed no difference of parenting style when comparing families with children with OC to others without an OC (Krueckeberg and Kapp-Simon, 1993; Speltz et al., 1993). We also found less conflict in families of children with OC than in those of controls, which contradicts the suggestion of Gothard et al. (1985) that children with special needs are more likely to be neglected or abused than are other children. Third, families of children with OC reported fewer recreational activities than the control families. This might be due to lack of interest in social pursuits, children being shy, inhibited, or depressed (Harrist et al., 1997), lack of support leading to "active isolation" (Endriga and Kapp-Simon, 1999), or fear of discrimination and stigmatization (Strauss and Broder, 1991; Ramstad et al., 1995; Marcusson et al., 2001). Frequently, combinations of these factors were observed also. Finally, families of children with OC showed a high level of independence, as well as good structure and organization.

Deviant facial appearance is readily noticeable and central in impression formation (Strauss and Broder, 1991). However, mothers in the "invisible" impairment group (ICP) more frequently reported that their children had difficulty making

friends than those of children with UCL/P or BCL/P. This finding might primarily reflect that children with ICP require more surgeries and their speech is more difficult to understand than their counterparts, thus making social interactions more difficult to achieve. This possibility is compounded by the fact that close to 62% of the ICP respondents noted that their child's condition was serious, whereas less than 30% of those responding for both cleft lip groups believed their child's condition had this level of severity. Speltz et al. (1993) described that visible impairment is associated with fewer family-friend and community contacts. In this study, close to 10% of mothers of children with cleft lip reported avoiding taking their children to social gatherings or taking pictures of their children, behaviors that were not mentioned by the mothers of the children with ICP.

The present study had some methodological shortcomings. First, the subjects were ascertained from a single craniofacial center in the suburbs of the city of Buenos Aires. It is possible, although unlikely, that the study participants did not represent the entire population of families of children with OC in this country. It should be noted, however, that the demographic distribution of the survey respondents (cases and controls) closely resembles that of the general population in Argentina. Second, several domains of family risk could not be assessed. For example, domains related to the child (e.g., cognition, temperament), parent and family variables (e.g., psychological well-being, marital satisfaction), and treatment variables (e.g., number and type of surgeries, therapeutic needs, and outcome of habilitation as it relates to factors such as speech, hearing, and appearance). A second phase of the study will incorporate questions to address these domains. Third, the number of participants in the ICP group was small, limiting our ability to make generalizations from such a small sample.

This study is the first to use the FES in families of children with OC and controls and the first to describe the social environment of families of children with OC in Argentina. Since family environment and family members' adaptation mutually influence each other, more research in this area is needed to design and deliver appropriate intervention programs.

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