

Self-Image Perception of 171 Children and Adolescents With Cleft Lip and Palate From 22 Countries

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ABSTRACT

Background: Cleft lip (CL) and cleft palate (CP) are among the most common congenital deformities of the head and neck. They are associated with many problems, physical and psychological. We describe 171 children and adolescents with CL/CP from 22 countries who were asked to draw their faces in a self-image perception drawing 2 hours before surgery to repair their deformities.

Methods: The aim of the study was to explore whether children and adolescents with CL and CP perceived themselves as deformed when given the opportunity to draw their faces before surgery to repair their deformities. Children were asked to lie down on a large piece of paper to have their body outline traced. Subsequently, the children were asked to draw their faces within the outline.

Results: All of the children included in this study drew their faces with normal mouths.

Conclusion: None of the 171 patients with CL/CP drew their deformity when asked to draw their faces; the reasons are not clear. The children may have wanted to compensate for their disability with the constructive use of fantasy as they anticipated the surgery to repair their CL/CP. An additional hypothesis is that the children felt the need to draw an image that they knew represented their parents' desires.

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INTRODUCTION

Cleft lip (CL) and cleft palate (CP) are among the most common congenital deformities of the head and neck. In the United States, CL occurs in 1/1,000 live births whereas CP occurs in 1/2,000 live births. CL deformities occur with the highest incidence among Native Americans (3.6/1,000 births), Asians (2.1/1,000), and Caucasians (1/1,000) and with the lowest incidence among blacks (0.41/1,000). In contrast, the incidence of CP does not differ among ethnic groups and occurs in 1/2,000 live births. CL occurs more commonly in boys than girls (2:1), whereas CP occurs more commonly in girls than in boys (2:1). Possible causes include maternal drug exposure, syndrome-malformation complex, and genetic factors.^{1,2}

Many problems are associated with CL/CP anatomic deformity, including otologic disease, speech and language problems, dental deformities, facial growth deficiencies, and social and psychological problems. The psychological problems associated with CL/CP anatomic deformity begin early in the child's life. Parents of deformed children frequently experience a loss of hope for having a healthy child, and these feelings may exacerbate the difficulties that some parents have in providing growth-promoting affective attunement to their child. The parents' anxiety is further increased because of their infant's impaired sucking abilities and articulation problems. Gradually, the child inevitably becomes aware that his or her body image is significantly different from that of others.³

Primary school-aged children with CL/CP have a lower self-concept, perceive themselves as less accepted by their peers, and are more sad and angry than a control group of their peers.⁴ Further, Kapp⁵ reported that CL/CP self-concept does not improve by adolescence; these children may not have developed social skills to establish peer relationships because of the stigma of their deformity; and they continue to be unhappy about their appearance, to be more anxious, and to perceive themselves as less successful

academically. Harper and Richman⁶ reported that children with CL/CP exhibited more inhibition in their personalities as measured by the Missouri Children's Picture Series.

No doubt, children with CL/CP struggle most of their lives with many insecurities. Perhaps the most difficult problem is becoming aware of their parents' discomfort with the child's disability.⁷ Tisza and Gumpertz³ reported that some children became well mannered and well behaved, *all good*, in an attempt to prevent their parents from creating further psychological and physical distance. Others developed externalizing behavior disorders as a result of poor self-concept and parents' detachment because of their children's deformities. Tisza et al⁸ believe that some children seem to intuitively recognize that good behavior improves the likelihood of maintaining their parents' love, and early in their lives they develop advanced ego-functioning abilities: using humor, isolating painful affect, and sublimating feelings of inferiority in being proactive with interactions with others.

Medical art therapy is a visual experience that allows the expression of fears and anxieties. This visual experience can be used as part of the healing process by facilitating body awareness.⁹ Art therapy has been integrated into the psychological treatment of children scheduled for surgery and children with medical conditions such as pediatric cancer and spinal cord injuries.¹⁰⁻¹² The information obtained by art therapy can be helpful in assessing children's personalities and supporting and counseling them.¹³

The aim of this study was to explore whether children and adolescents with CL/CP perceived themselves as deformed when given the opportunity to draw their faces before surgery to repair their deformities.

METHODS

As part of an international medical mission, 171 children from 22 countries (Table) who lived in areas with little access to medical care participated during the years 2000 through 2007 in an art therapy session with a licensed art therapist 2 hours before their reparative CL/CP surgery. The children were asked to lie down on a large piece of paper to have their body outline traced. Subsequently, the children were asked to draw their faces within the outline.

RESULTS

Of the 171 children studied, 70% were male and 30% were female. Ages ranged from 5 to 17 years. The most striking finding is that 100% of the children included in this study did not draw their CL/CP when asked to draw their faces; rather, they drew normal mouths.

Table. Number of Children From Each Country Included in This Study

Country	No.	%
1. Australia	1	0.58
2. Botswana	10	5.84
3. Canada	55	32.16
4. Ecuador	2	1.17
5. Egypt	12	7.02
6. England	4	2.34
7. Ethiopia	5	2.92
8. France	2	1.17
9. Ghana	5	2.92
10. India	3	1.75
11. Iran	1	0.58
12. Ireland	3	1.75
13. Israel	4	2.34
14. Jamaica	1	0.58
15. Jordan	10	5.85
16. Kenya	8	4.68
17. Mexico	6	3.51
18. Morocco	6	3.51
19. Spain	2	1.17
20. Syria	1	0.58
21. United Arab Emirates	5	2.92
22. United States of America	25	14.62
Total	171	99.81^a

^aNot equal to 100% due to rounding.

DISCUSSION

The psychological development of children with CL/CP is complex because of many interrelated factors, such as the parents' level of acceptance of the handicapped child and their capacity to mourn the loss of their wish for a healthy, nondisfigured child. If the parents had healthy children prior to the birth of the child with CL/CP and healthy patterns of attachment became familiar to them, the parents' attachment working models with a child with CL/CP are less conflicted. Other factors that contribute to the child's psychological development are the nature and extent of the handicap, the medical ramifications, the support from other family members, and the social environment.

The first use of art therapy as a treatment intervention was in the psychiatric population. It is now a common form of therapy for patients in hospitals and specialty clinics. The goal of art therapy is to use visual material to help people understand the source of emotional distress in the hope of improving their coping skills and subsequently improving their outcomes.¹⁴

Art therapy is used in a variety of pediatric medical populations, including patients with cancer, kidney

disease, juvenile rheumatoid arthritis, chronic pain, severe burns, asthma, and eating disorders. The creative process can empower children undergoing medical treatment by providing a vehicle to work through anxieties about their illness. When “children engage in art making, they are in charge of the work—the materials to be used; the scope, intent, and imagery; when the piece is finished; and whether it will be retained or discarded, all these factors are under the child artist’s control.”¹⁰ S. Bach, a pioneer in art therapy for children, collected pictures drawn by hospitalized children and developed a system of analyzing the children’s artwork to aid in understanding the disease processes and predicting treatment outcomes. She believed that the processes of physical healing stemmed from the children’s “inner knowingness” about the state of their bodies.¹⁰ Bach’s work challenged art therapists to remain open to the expression of children’s unconscious through art.

When the CL/CP multidisciplinary team includes medical art therapy as part of the treatment plan, the children use art to communicate perceptions, anxieties, fears, and wishes to the art therapists. When art therapists share the information with mental health professionals, child life specialists, and the multidisciplinary team, they are better equipped to treat the *whole person*, not just the medical condition. The information can be extremely useful in tailoring support and counseling by assessing the child’s ego-functioning, personality style, and cognitive level. Participating in creative work within the medical setting can help rebuild the young patient’s sense of hope, self-esteem, autonomy, and competence while offering opportunities for safe and contained expression of feelings.

In addition, a multidisciplinary team’s display of optimism toward children about the likely outcome of the medical treatment further influences positive and hopeful attitudes. Building an image of a healthy child through art, a uniquely human act of creating meaning out of formless materials, can be a powerful vehicle for the child with disabilities to rebuild a sense of well-being. Providing hope can help children overcome anxieties: “Children who think hopefully can imagine and embrace goals related to the successful treatment of their physical problems.”¹⁵ Offering familiar materials with the skilled therapist’s support can reassure the child with physical deformities that he or she is still a person with a great deal to offer. Kramer¹⁶ recognized the intrinsic power of the artistic process to bring order to the chaos within. The access to art therapy by physically or emotionally ill children provides the support that can help mitigate the negative reactions to stressful circumstances.

The reason why 100% of the children and adolescents in this study did not draw their CL/CP is unclear because a follow-up interview was not possible. Nevertheless, the results suggest that the drawings may be the children’s attempts to compensate for their disability with the constructive use of fantasy while anticipating the surgery to repair their CL/CP. Another possibility may be that the drawings without the CL/CP represent the image their parents desired. We believe that these findings support early reports of some children with CL/CP who demonstrate signs of pseudomaturity: “Youngsters born with clefts are ‘good’ children and excellent, uncomplaining patients,” and they “express no fear of doctors or medical procedures.”¹⁷

This study has several limitations. Information was limited regarding the child’s premorbid functioning, family situation, and social skills. The comments made by these children when asked about their impressions of their drawings were not available. In some cases, interpreters were needed, which may have affected their performance if the directions were not understood. Furthermore, we had no control group of drawings of children with repaired CL/CP. Additional studies are needed to better understand the reasons why children across the globe denied their CL/CP in drawings when asked to draw their faces. We suggest the study of a parallel group with the children’s parents drawing their perception of their children’s faces prior to surgery. This effort may lead to early parent-child intervention to improve self-esteem for both child and parent after the surgery. Whether issues of socioeconomic status affected these children also warrants study.

CONCLUSION

When asked to draw their faces, 171 patients with CL/CP did not draw their deformity. The reasons for this are not clear; we believe that the children may have wanted to compensate for their disability with the constructive use of fantasy as they anticipated the surgery to repair their CL/CP. In addition, the children may have felt the need to draw an image that they knew their parents wanted to see. Our study was an initial exploration of this interesting topic. Additional studies are needed to further evaluate these findings.

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