The Social Effects of Craniofacial Deformity and its correction

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A survey of our first 50 patients having *craniofacial surgery* was done. An attempt was made to determine the *impact* of *facial deformity* on *social function* for both the patient and his family and how function was altered by surgical correction. This was accomplished by a uniform series of questions. All patients were at least one year postoperative.

The results emphasize that facial deformity played a dominant role in patients' lives prior to surgery and that surgical intervention led to improved social functioning in a number of areas. Meaningful data was collected on three groups of patients: 11 adults, 18 adolescents, and 17 children. Changes perceived were strikingly different in the three groups. Eighty-seven percent of all patients would make the decision to have surgery again, and at least 50 percent had objective evidence of improved function. However, the survey also suggests that the extreme stress produced by the treatment may create family problems for which support is necessary.

Background

The emphasis on physical appearance and the intolerance for difference in our culture leads to the expectation that facial deformity will affect personality. The relationship between the facially deformed and the society in which he or she lives might likewise be affected. We look to the face for expressions of emotions as well as social reactions. Macgregor (1951) pointed out that looking at one another is a basic form of communication.

Social psychologists tell us that one's social reality depends in large measure on other people's ideas of what is acceptable. What is the social reality and what are the group pressures for the deformed person? Such people are often treated by society as having minority status, with prejudice and discrimination. This may lead to difficulties in establishing friendships, sexual relationships, and in employment situations.

In his search for data on the psychosocial aspects of the lives of other disabled persons, Clifford (1973) reported that "evidence does exist that anomalies are deterrents to establishing more intimate social relationships," and Pinner (1963) indicated that evidence of "frustrations of vocational goals does exist."

There are no formal studies on the psychosocial effects of craniofacial deformity and its correction. However, there are a few studies available describing the psychological and social effects of minor facial deformities and their correction (Clifford, 1972; Edgerton, 1960; Knorr, 1968; Meyer, 1961). These studies generally indicate that patients view surgical correction as helpful.

A major study, which is referred to consistently, is that done by Macgregor (1953). This work, based mainly on extensive interviews, documents that those patients with facial disfigurement see themselves in a minority status. Her patients reported that surgery made them feel and act differently. One would expect to find similar results for correction of more major facial deformities.

The psychological benefits of making a grotesque face appear more nearly normal seem obvious. It has been hypothesized that, following surgical intervention, improvement in social functioning and personality may occur.

This paper was presented at the Third International Congress on Cleft Palate, June 5–10, 1977, Toronto, Canada.

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Indeed, this has been described as the greatest potential benefit of craniofacial surgery.

The purpose of our survey was to explore the impact of craniofacial surgery on the lives of those who had had the surgery and on their families. We attempted to determine: (a) if surgery led to change in social functioning of the patients studied; (b) what the impact of the surgery was on the family; and (c) if providing emotional support would alter perceptions of surgical change. We did not attempt an in depth exploration of the impact of the surgery on the families. Only one question was addressed to this issue. Concentration of effort was on subjects who had had craniofacial surgery one year or more prior to the survey. Follow-up after longer periods of time will be necessary.

Methodology

The hypothetical social and/or personality changes following craniofacial surgery may be influenced by several variables such as: age of patient, severity of deformity, length of time since surgery, and whether or not the patient has had previous surgery or hospitalization. There was no way to control these variables in this study since the available population was quite diversified. It should be noted, however, that this same diversification would be found in any series of surgically managed craniofacial patients.

A survey which attempted to measure postoperative role, behavior, and attitudinal changes among patients of different age groups and their families was selected. An interview format of uniform questions was developed (Table 1). It was designed to elicit evidence of behavioral and affective changes. Social behavioral functioning was measured by recording any behavioral or role changes the patient had made, such as changes in job, school grades, or dating, and the addition of new activities or the resumption of activities previously dropped. Affective changes on the part of the patient or changes in the affective responses of others were also included. Such things as decreased staring in public, less teasing, more positive comments, increased self-confidence, and feeling more attractive were included. The interview format was pretested on the parents of one child not included in this survey. Each person interviewed had an equal opportunity to respond to these questions. All interviews were done by one person (J.P.).

All adult and adolescent patients and parents of children and adolescents were contacted by letter to inform them of the survey and were requested to participate prior to telephone contact. Because of time and geographical limitations (15 patients lived more than an hour away from Philadelphia), interviews were conducted by telephone.

Since only a small number of children were of school age at the time of surgery, they were grouped with preschool children. Because of the very young ages of many children and the fact that interviews were conducted on the telephone, only the parents of children under 12 were interviewed, rather than the children themselves. With adolescents (ages 12–18), both the patient and one parent were interviewed. All adults were interviewed, but not their parents. The usual interview lasted half an hour.

During the four-year period 1972–1976, approximately 100 people were operated on for correction of craniofacial anomalies at the Hospital of the University of Pennsylvania and the Children's Hospital of Philadelphia. The sample for this survey includes only the first 50 patients. No patient was interviewed if surgery had not been done before August 1975. This allowed a minimum time of one

TABLE 1. Questions asked.

1. How was the decision to have surgery made? What was your expectation?
2. Has there been any difference in your (your child's) life at school (work)? Did you expect change?
3. Has there been any difference in your (your child's) social life? Did you expect change?
4. Has there been any difference in your family life? Did you expect change?
5. Has there been any difference in your (your child's) personality or feelings about your self? Did you expect change?
6. Is anything worse in your life as a result of surgery? Did you expect change?
7. When you got nervous during the hospitalization, who or what helped?
8. Would you make the same decision about surgery again?
9. Did the surgery meet your expectations?
10. What would you tell other people thinking about having the surgery?

year after surgery prior to the interviews. Ten patients were operated on by Dr. Paul Tessier or Dr. Peter Randall and the remainder by Dr. Whitaker. Five of the fifty had had surgery to correct deformities that resulted from trauma. All others had craniofacial anomalies that had existed from birth. There were 17 with craniofacial dysostosis (Apert or Crouzon's), 15 with hypertelorism, and 10 with Treacher-Collins Syndrome.

Results

Of the 50 people to whom letters were sent, only three could not be contacted. Consequently, the results include data on 47 patients, including 11 adults, 18 adolescents, and 18 children.

Details of the interview findings for each age group have been broadly categorized into three areas. These have been identified as (1) the decision-making process; (2) the surgical experience, and (3) changes in function and interaction of the patient and family. The findings for each age group are given in Tables 2, 3, and 4 and, for all groups, in Table 5.

THE DECISION-MAKING PROCESS In most instances in children under 12, parents made

TABLE 2. Results of psychosocial survey children <12 years age*.

	# with findings	*total # pts*	%
I. The Decision			
A. Who made it:			
Parents	14	18	77
Others	4		23
B. Would do again:	17	18	94
Not sure	1		6
C. What to tell others**			
Have it for child	6	18	33
Have it but tell about post-op and long recovery	2		11
II. The Surgical Experience			
A. Most important in hospital support			
Parent services	11	18	61
Medical staff	4		23
Other	3		17
B. Recovery period concerns***			
Temporarily worse	3	18	17
Post-op and long recovery	2		11
C. Surgery met expectations	15	18	83
No or unrealistic expectations	3		17
III. Changes in function			
A. Feelings about self			
Parents not sure how child feels	9	18	50
Still self-conscious	3		17
Better	6		33
B. Difference in life at school or work* and ***			
Behavioral improvements (grades)	1	6	16
Affective improvement (less teasing, more calm)	3	6	50
C. Difference in social life ** and ****			
Behavioral (new activities)	3	12	25
Affective (less teasing, staring, more + response)	11	12	91
D. Difference in family relations			
Behavioral (one child adopted after surgery)	1	18	6
Affective (parents less protective, feel better)	11		61

* Of 18 children 12 years of age and under, only 6 were in school at the time of surgery.

** Of 18 children 12 years of age and under, 6 were infants or toddlers.

*** Totals of less than 100% indicate that only the percentage listed responded to the question.

**** Totals more than 100% because both behavioral and affective changes often noted in same patients.

TABLE 3. Results of psychosocial survey adolescents (13–18 yrs.)

	adolescents			*parents*		
	# with findings	*total # pts*	*%*	*# with findings*	*total pts*	*%*
I. The Decision						
A. Who made it:						
Adolescent and parents	12	18	67	13	18	72
Parents	6		33	5		
B. Would do again:	14	18	78	16	18	99
Not sure	4		22	2		11
C. What to tell others						
Have it for child*	5	18	28	6	18	33
Have it but tell about post-op and long rec.	9		50	8	18	44
II. The Surgical Experience						
A. Most important in hospital support*						
Parent services				9	18	50
Medical staff	10	18	56	5		28
Family	8		44			
B. Recovery period concerns**						
Temporarily worse	1	18	6	1	18	6
Post-op and long recovery	9		50	8		44
C. Surgery met expectations	14	18	77	9	18	50
Half way or no	4	18	23	9	18	50
III. Changes in Function*						
A. Personality or feelings about self						
Behavioral improvement (stopped hiding face)	0	18	0	1	18	6
Affective improvement (more self confident)	11		61	8		44
More self consicous and shy	1		6	1		6
B. Difference in life at school or work						
Behavioral improvements (grades)	3	18	17	0	18	0
Behavioral loss (worse grades)	2		11	0		0
Affective improvement (better relations)	7		38	8		44
C. Difference in social life						
Behavioral (new activities)	6	18	33	4	18	23
Affective (more friends)	10		56	7		38
Worse	1		6	1		
D. Difference in family relations						
Closer to parents	2	18	11			
Parents feel better about trying to help				7	18	38

* When totals less than 100% remainder did not respond to question, response, was uncertain, or no change was noted.

** The remainder did not express unusual recovery period concerns.

the decision for surgery (77 percent) and friends or relatives in most of the remainder. Adolescents participated as the dominant part of the decision-making process 67 percent of the time, and all adult patients considered the decision to have been their own.

Over 50 percent of the parents and patients emphasized the importance of in-depth discussion in the decision-making preoperative period. In particular, they felt that the long postoperative recovery period, the fact that patients may be temporarily worse during that period, and the marked swelling and discoloration postoperatively should be emphasized.

Surgical Experience During the recovery period, the immediate family was particularly important to children and support services (nursing and social work) were of special help to the parents. In adolescents, the medical staff were thought to be the greatest source of support 57 percent of the time with the family being named 44 percent of the time. In the adult, the medical staff was considered to be

TABLE 4. Results of psychosocial survey adults.

	# with findings	*total # pts*	%
I. The Decision			
A. Who made it:			
The patient	11	11	100
Other	0		
B. Would do again	10	11	91
Not sure	1		9
C. What to tell others			
Have it but tell about recovery*	5	11	45
II. The Surgical Experience			
A. Most important in hospital support			
Medical staff	9	11	81
Family and others	2		81
B. Recovery period concerns			
Temporarily worse	0		
Post op and long recovery			
C. Surgery met expectations	9	11	81
Half way, had unrealistic expectations	2		19
III. Changes in Function			
A. Personality or feelings about self			
Affective improvement (more self confident, sexually attractive)	10	11	91
B. Difference in school or work			
Behavioral improvement (resume activities of new work)	3	11	27
Affective improvement (better relationships)	3		27
Worse	0		
C. Difference in social life			
Behavioral improvement (new activities, resumed activities)	3	11	27
Affective improvement (easier to mix, more sexually active)	8		73
Worse	0		
D. Difference in family relations			
Behavioral improvement	1	11	9
Affective improvement	3		27
Worse	0		27

* When totals are less than 100% no changes were noted for remainder or no response was given.

the most important for 81 percent of the patients.

Thirty (64 percent) felt "better" for having had the surgery and only one felt worse. Overall results indicate that forty-two people (89 percent)—both patients and parents reported some improvement. One person reported an observable negative change and four "no change" (Table 6).

CHANGES IN FUNCTION OF PATIENT Thirteen people (27 percent) (three children, six adolescents, and four adults) reported observable, measurable, behavioral improvements in social functioning that they attribute to having had surgery (Table 7). These changes include those described above: working more in the public view, improved grades, participation in new activities, increased dating, and easier mixing. One adolescent was "worse" following surgery, and the remainder had no measurable behavioral changes.

In addition to changes in social functioning, many people reported affective or attitudinal changes. Less teasing by other children was reported by 50 percent (9) of the parents of children 12 and under, and a total of 94 per cent (17) of parents reported some form of affective improvement. Most parents of children 12 and under didn't know what their children felt about themselves subjectively,

TABLE 5. Results of psychosocial survey all age groups.

	results		
	children N-18 percentage	*Adoles. 18 percentage*	*adults 11 percentage*
I. The Decision			
A. Who made it			
Patient with other person	4 (23)	12 (67)	11 (100)
Parents alone	14 (77)	6 (33)	
B. Would do again	17 (94)	15 (84)	10 (91)
Not sure	1 (6)	4 (23)	1 (9)
C. What to tell others			
Have it	8 (44)	14 (77)	5 (45)
II. The Surgical Experience			
A. Most important in hospital support			
Parent services	11 (61)		
Medical staff	4 (22)	10 (57)	9 (81)
Family and friends		8 (43)	2 (18)
B. Recovery period concerns			
Temporarily worse	3 (17)	1 (6)	0
Post op and long recovery	2 (11)	9 (50)	0
C. Surgery met expectations	15 (83)	14 (77)	9 (81)
Halfway or unrealistic expectations	3 (16)	4 (22)	2 (18)
III. Changes in Function			
A. Difference in person's own feelings about self or personality			
Feel better	9 (50)*	11 (61)	10 (91)
Feel worse	0	1 (6)	0
Not sure	9 (50)	6 (33)	1 (9)
B. Difference in school or work			
Behavioral improvement (grades, new work plans, new activities)	1 (16)**	3 (16)	3 (27)
Affective improvement (better relationships, less teasing)	3 (50)	7 (38)	3 (27)
Worse	0	1 (6)	0
No change or not sure	2 (33)	7 (38)	5 (45)
C. Difference in social life	2 (33)	7 (38)	5 (45)
Behavioral improvement (new activities)	3 (25)***	6 (33)	3 (27)
Affective improvement (more friends, less teasing)	11 (91)	10 (57)	8 (73)
Worse		1 (6)	
D. Difference in family relations			
Behavioral improvement	1 (6)		1 (9)
Affective improvement	11 (61)	9 (50)	3 (27)
Worse	0	0	0

* Parental assessment of child.

** Six children were school age.

*** Twelve children were 3–12 years of age.

but 55 percent of adolescents and 91 percent (10) of adults reported feeling better about their appearances or more confident. This was reflected in improved school or work performance and social functioning. One adolescent felt worse about his appearance. Family relations were reported to be improved following surgery in the majority of instances.

It is striking that, although surgery is not "medically necessary," most parents of children 12 and under "felt it had to be done," and several parents of adolescents felt it was important to try to help their children. Such an attitude may indicate the strength of social pressure toward conformity. It certainly indicates the importance of surgery to parents as well as to children and emphasizes the importance of determining the child's or the adolescent's desire for surgery as well as that of the parents.

When asked whether they would have surgery again, 91% of parents of young children, 77% of adolescents and 91% of adult patients, or 89% of all individuals interviewed said yes (Table 7). Those reluctant to undergo surgery again cited the prolonged recovery period, shaved heads, discomfort, and occasionally disappointment with the surgical result as the major reasons for not wanting to repeat the experience.

Impact of Major Facial Surgery on the Family Just as the impact of craniofacial surgery on the lives of the patients has not been evaluated, neither has the effect of the surgery on the family unit. Surgery is imposed as a reconstructive-esthetic procedure, usually only for the purpose of improving the quality of life and not for the correction of a life-threatening situation. Thus, families are confronted with a highly unusual situation requiring a decision probably unlike any previously encountered in medicine.

TABLE 6. Psychosocial changes composite results.

Improvement in one or more areas reported by patient or family	42/47 (89%)
"No change"	4/47 (7%)
"Worse"	1/47 (2%)
Would have surgery again	42/47 (89%)

If one looks at the family as a unit, the effect of medical treatment of one family member on the total family becomes evident. Families have certain patterned activities. Family members are interdependent. Thus a change in one member of a family has an effect on all other members of the family. Increased attention to one child may mean that parents have less time for each other and less time for their other children. Thus, the goal of one member of the system may not be compatible with the goals of the total system (Katz, 1966).

Since the maintenance of family activities requires a continuous input of energy, one must consider the consequence of a two-year long input of additional stress. Two years is necessary because it takes one year for completion of wound resolution and often revisions are necessary. Families with many resources (either material or emotional) may survive this process of additional stress and delayed outcome. However, this experience could lead to family breakdown when there are fewer resources available. The impact of craniofacial surgery on the family is a critical consideration. It is initially experienced in several ways, which seem to be related to the tension of the surgery itself and to the long recovery period. An adjustment period then seems to occur.

After making the original decision to take the risks, there is the hospitalization, including several days in intensive care. Hospitalization may mean financial stress. It also brings the usual disruptions in family schedules and necessitates child provisions for the care of other children. For families who do

TABLE 7. Psychosocial function changes all ages.

	children		*adolescents*		*adults*	
	#*	%	#*	%	#*	%
Behavioral improvement	3	16	6	32	4	36
Negative change			1	6		
Affective improvement	17	91	10	55	8	73
Negative change			1	6		
No reported impairment in psychosocial function	16	83	15	77	9	81
Temporary problems	3	16	1	6	2	18
Would make same decision again	17	91	15	77	10	91

* 18 children, 18 adolescents and 11 adults.

Remaining percentages in each category reported no change.

not live in the local area, it may mean traveling and hotel expenses.

In addition, initially, the person looks worse than he did before surgery. He often has no hair and there is distortion from swelling of the head and facial tissues. This swelling can take months to subside completely. Some patients have their jaws wired, which means temporary eating problems. During all of this, there are frequent medical appointments. To compound the problem, one or more subsequent operations may be necessary for many patients.

Considering the operative and recovery phase of the surgical experience, 61 percent of parents, adolescents, and adults thought that it would be desirable for the professionals to be honest and tell people how difficult the hospitalization and recovery period will be. Several patients and family members reported that it had been helpful to them to talk to former patients. Several others expressed a wish for this opportunity. Most people seemed to have understood the risks of surgery itself, but most felt unprepared for the real impact of swollen faces, shaved heads, wired jaws, and long recovery periods, regardless of the amount of preoperative explanations.

In response to the question, "If you had it to do over again, would you have the surgery?," many parents of children 12 and under and adolescents initially hesitated. When this was followed with, "Was the surgery worth it?," most said "yes" (89 percent). However, these answer patterns indicate the stress of the process. One gets the feeling that it is only desperation for change that makes the stress endurable. In spite of the fact that all of this had been explained, intellectual knowledge is very different from emotional understanding. *It may not be possible to accomplish complete psychological preparation for this surgery, but it is possible to provide support to people as they go through the experience by having social workers and others available to help.*

Follow-up requires being seen by "all relevant specialists." This is a simple statement of a complicated process. Relevant specialists easily include a half-dozen people. This means a patient and/or parents may need to be seen at times in as many as six different places in the hospital. It can be an exhausting experience, sometimes with several appointments on one day, or multiple visits on different days. All of this means increased stress for the family. With the normal stresses of childhood and adolescence, one must consider the impact of placing additional stress on the system. In addition, the desperation for change people must feel in order to elect to have such radical surgery probably further accentuates the difficulty of waiting as long as a year or two for results. Another problem (Meyer, 1961) is the period of recovery after plastic surgery:

> The patient not only must be told the actual facts of what the surgeon can do but must really hear what is said. This applies with particular force to the operative procedure itself and to the details of the immediate postoperative period. Patients may have and frequently do have highly distorted or fantasy endowed conceptions of the surgical procedure in spite of what they have been told.

This emphasizes an additional difficulty, that of the patient being realistic about what can be achieved and what is required to achieve it.

Discussion

Most people (89 percent) reported some improvement as a result of surgery, and indeed, 89 percent said they would have the surgery again. However, perception of improvement seems to be influenced heavily by other factors such as how the decision to have surgery was made and how long recovery took. The person making the decision seems particularly important in the case of adolescents. Indeed perception of improvement seemed to be heavily influenced by this and several other factors. These included, in addition to who made the decision, how the decision was made, and length of recovery. One young man for example, denied any difference in his life. However, when questioned further, he admitted that he "looks better and feels more confident." His reluctance to acknowledge change seemed to be related to not having participated in the decision-making. Another young man who did participate in the decision-making but whose surgery was followed by complications and was consequently not as successful, was more positive in his response.

Perception of change was often strikingly different between adolescents and their parents. Several times a mother reported she did not see any difference in her sibling's personality or feelings about himself, e.g., the individual had always been a little shy but still had friends and activities. A short time later, the adolescent in question would describe that he used to feel depressed and/or shy but now felt much less shy. This difference in response points to the difficulties in the analyses and must be kept in mind when parents of young children tell us they do not think the child is aware of the difference. It also emphasizes the importance of talking to adolescents separately from their parents.

Clearly, the surgery is as important to parents as to the patients themselves. The fact that 92 percent (33/36) of parents of children and adolescents said they would make the same decision again, even when surgery did not meet all of their expectations, indicates how important it is for them to try to help their children. As noted previously, most parents "felt that it had to be done" in spite of the fact that it was not "medically necessary." Since the family relationship is so significant for the young child, one cannot ignore the importance of parents' feeling relaxed with their child. Several parents who acknowledged that they had spoiled their children or had been overprotective reported that they were beginning to change their behavior since surgery.

Attention must be given to the importance of affective as well as behavioral changes even though these are less observable and more difficult to measure. We know that it takes some time to incorporate a new body image. Since the recovery period for this surgery is so long, it may be impossible to see the effects of surgery for one or two years, or even longer.

Recommendations

It seems likely that most children and families could benefit from some structured support throughout the treatment process. The relationship with the surgeon has provided the main support to families thus far. This relationship seems invaluable and, probably, irreplaceable. However, physicians cannot possibly provide all the complicated psychosocial support needed. The importance of the social worker and/or psychologist as regular members of the Facial Reconstructive Team is emphasized by this study, and they should be involved throughout the duration of the treatment process.

Summary

The results of this survey suggest that surgical intervention did lead to feelings of improved social functioning for a majority of the cases studied. This was perceived to be true by 89 percent of our patients and families. Of additional importance, 89 percent would have the surgery again, only one (2 percent) felt that he was worse following surgery. However, the extreme stressfulness of the treatment efforts could lead to family problems and consequent lack of support to the patient if a supportive structure is not provided.

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