Perceptions of Appearance and Speech by Adolescent Patients With Cleft Lip and Palate and by Their Parents

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This study surveyed 102 patients with cleft lip, cleft palate, or cleft lip and cleft palate (ages 13 to 19) and their parents to assess satisfaction with appearance, speech ability, and intelligibility. The data were based upon standardized interviews conducted at a cleft palate treatment center, using simple questions with high face validity. Surgical experience was high among this sample, as reflected by the finding that the majority of patients (55.7%) had had three or more operations on the face or mouth. Patient ratings of facial appearance showed that most patients were very pleased (59.3%) or moderately pleased (13.2%); others were somewhat (18.7%) or very (8.8%) disappointed. Many parents indicated that their children expressed occasional (22.0%) or frequent (27.5%) concerns about appearance. Nearly all patients (91.9%) felt that their operations had accomplished what they expected, though some of the cleft lip patients (35.7%) and their parents (43.9%) were less than very pleased with the appearance of the lip.

When asked how pleased they were with the way they presently talked, most patients (69.1%) were very pleased, though some disappointment was expressed. Although often pleased with their current speech status, many patients rated themselves as only moderately understandable (19.1%) or as not understandable (8.5%). No significant gender effects were found in satisfaction, appearance, or speech ratings. There were no significant differences found between parent and child ratings. The findings indicate that at a center delivering team-based cleft palate care, both adolescent patients and their parents have considerable concerns about appearance and speech results.

KEY WORDS: adolescents, appearance, speech, satisfaction.

This study employs self-report and parent interview data to describe the concerns and attitudes toward treatment among 102 adolescents with cleft of the lip, cleft of the palate, or both. Assumptions that adolescents with clefts are generally well pleased with their appearance and speech have not previously been fully tested. This study is important because it underscores the potential concerns of adolescents, a sometimes forgotten population. Adolescents with cleft must cope with maturation and the usual problems surrounding self-identity while dealing with particular self-concept questions and treatment decisions.

Goffman's (1963) theory of stigmatization holds that persons with physical disabilities are socially discredited and have reduced self-esteem. They respond to the values and judgments of 'normals' by internalizing how they are socially 'seen' and thus develop negative self-perceptions. The blemish that initiates stigmatization may be remediated by medical treat-
The research literature is inconclusive about how adolescents with cleft may differ in self-satisfaction and self-concept from adolescents without cleft (Richman and Eliason, 1982). Brantley and Clifford (1979) compared 100 adolescents without cleft, 51 adolescents with cleft palate, and 22 obese adolescents on dimensions including body image and self-concept. They found that adolescents with cleft reported a comparatively higher level of self-confidence and self-esteem as compared with subjects without cleft, yet they also expressed feelings to their parents that others were not accepting of them. Brantley and Clifford (1979) speculated that the challenge of coping with the cleft as a handicap may have resulted in higher self-esteem. Kapp's (1979) study, which used the Piers-Harris Self-Concept Scale on 34 adolescents with cleft, reported that although their overall self-concepts were adequate, patients were less satisfied with their physical appearance than peers without cleft. Kapp (1979) found that females expressed a greater degree of unhappiness and dissatisfaction, achieved less success in school, and experienced more anxiety than did males. Harper and Richman (1978), using the MMPI, reported no significant psychopathology among 52 adolescents with cleft, but females displayed greater dissatisfaction with their life situation than did males. The investigators interpreted the gender difference as a response to a greater social emphasis on attractiveness in females during the adolescent period.

Richman (1983), examining 30 adolescents with cleft lip and palate, found that they were generally well adjusted, but a significant number reported concerns about facial appearance. Facial appearance was judged more central than was speech. Richman's findings suggest that most adolescents with cleft are well adjusted; however, there is a group who do experience adjustment problems, often related to their appearance and who desire further facial surgery. Richman et al (1985) examined 36 adolescents with cleft, separating them into categories of well-adjusted and poorly adjusted, based upon parental ratings of their behavior. The well-adjusted patients held self-perceptions similar to the perceptions of their parents and teachers, whereas those who were poorly adjusted saw themselves as more facially attractive than did teacher-raters and as less socially inhibited than did their parents. The study raises questions about the validity of self-report measures but again supports the finding that some adolescents have significant and cleft-related adjustment and behavioral problems.

The literature indicates uncertainty about how having a cleft might influence satisfaction and self-perception among adolescents. Aspects of self-concept have been shown to be affected in adolescent patients with cleft, but there is no evidence that this is associated with psychopathology. The possibility has been raised that patients and parents hold different views about the status of the adolescent with a cleft. This project was undertaken to establish levels of satisfaction among adolescent patients and their parents. The research literature has not compared parent and patient evaluations of appearance and speech, nor has it replicated Richman's (1983) finding that appearance is more problematic than speech to adolescents with cleft lip and palate. This investigation seeks to elaborate on the previous literature by examining satisfaction and perceptions of speech and appearance among adolescents with cleft and their parents.

METHODS

The questions used in this study are part of a longitudinal data registry developed for team evaluation of patients in an orofacial treatment center. The questions have been utilized over an 11-year period and were selected for clarity and ease of response. The questions were extensively pre-tested in the clinic context, and no modifications in the instrument occurred during the study period.

A structured personal interview format (see Appendix) was used with 102 patients with cleft lip, cleft palate, or both, aged 13 through 19. The interview consisted of a uniform and specific series of questions for both patients and parents. The interviewer coded answers into established categories but did not offer response choices. Responses to the satisfaction questions were coded into one of five possible categories. Responses to interview questions regarding the patient's problems allowed for coding of "no problem" separately from a response of "don't know/unable to evaluate."

All subjects were evaluated at a large cleft palate treatment center as part of an initial visit or recall protocol. The interviews were conducted privately by an experienced interviewer who was trained by the senior author. Training included formal review of the questionnaires as well as observing the interviewer during her administration of the questions. The interviewer was proficient in regional dialect, skilled at putting people at ease, and did not wear clinical
attire. Her nonprofessional identity made her approachable and enhanced the nonthreatening aspects of the interview process. Only one interviewer was used to reduce concerns about inter-rater reliability. Closed-ended questionnaires utilized by skilled interviewers are a valuable method for the collection of social and psychological information. Questions that had high face validity (see Appendix) were chosen, and no formal scales or tests were employed in the interview because of the lack of appropriate instruments in the literature. Scales of satisfaction with health care are quite general and do not offer the specificity that is required for the study of cleft lip and palate. An interview-based questionnaire was chosen because it limits errors of comprehension that often plague self-administered and mailed questionnaires and affords a subject an opportunity to clarify a question. The use of interviewer coding allows the respondent to answer in his or her own words and the interviewer to then categorize the response. It is common for the interviewer to verify the coded response with the respondent by "feeding" the categorized response back. This feedback method enhances the reliability of responses and reduces potential coding errors. Each patient was interviewed early in the day of their having a team-based evaluation. Patient interviews are commonly followed by private interviews with the parent or parents who accompany the patient.

As part of this evaluation, patients receive a 1-hour speech and language assessment. They are also all seen for independent assessment by pressure flow testing in a laboratory setting. Speech ratings are derived from the report generated by two speech pathologists and are based on 6-point rating scales entered on a form that is routinely used for processing speech data as part of the data registry for team patients. Reports to local speech pathologists and other professionals are based upon these ratings. The speech pathologist's findings are derived from observations of speech, recordings, and parent/patient reporting. Various speech and language testing instruments are utilized as deemed necessary by the professional. Speech evaluation includes a physical examination, with ratings of hypernasality, hyponasality, nasal obstruction, nasal emission, facial grimace, vocal intensity, overall velopharyngeal function, articulation problems, intelligibility, language skills (receptive and expressive), voice quality, dysfluencies, and articulation errors.

**SAMPLE CHARACTERISTICS**

This study is descriptive of a special clinical population and does not make comparisons with control normals. The study sample was composed of 102 patients with cleft, aged 13 through 19. The mean age was 15.2 years. Fifty-seven (N = 58) percent were male. No patients with craniofacial or other diagnosed syndromes were included. The sample included 43 patients with cleft lip and cleft palate (42.1%), 14 patients with cleft lip alone (13.7%), and 45 patients (44.1%) with cleft palate alone (including submucous cleft of the palate). The sample is made up of consecutive adolescent patients (receiving a team-based evaluation) with cleft over a 4-year period. Typically, adolescents with cleft are seen every 2 to 3 years for a team-based evaluation. The racial breakdown of the sample was as follows: white, 80.4% (N = 82); black, 16.6% (N = 17); and other, 2.9% (N = 3). A group of the adolescent patients (7.8%, N = 8) had reduced mental ages and were functioning in the mild range of mental retardation. The population that utilizes this clinic includes families from all socioeconomic groups. Examination of reported family income reveals that there is a slightly higher representation of low-income families compared with the North Carolina Census. This finding is related to North Carolina Children's Special Health Service's reimbursement to this team for provision of cleft lip and palate treatment in low-income families.

Parent reports indicated that nearly all patients have received orofacial surgical care. The number of plastic and oral surgical procedures per patient is displayed in Figure 1. Nearly half (46.6%) of the patients had four or more oper-
ations, with four patients having had 10 or more procedures. The number of surgical procedures depended upon cleft diagnosis. Patients with cleft lip and palate underwent the highest number of surgical procedures, and those with isolated cleft palate underwent the lowest number of procedures.

Speech pathologists rated intelligibility (on a 6-point scale) as normal in 72% of the patients, as mildly to moderately impaired in 26%, and as severely or moderately to severely impaired in 2%. Resonance quality was assessed with pressure flow testing, with subjects assigned to one of six possible categories. Findings revealed that 69% were normal, 19% were slightly hypernasal, 8% were found to exhibit moderate to gross hypernasality, and an additional 3% were hyponasal. No significant gender differences were noted in speech pathologists' ratings.

RESULTS

Indicators of Satisfaction

When asked whether the operations to the face and mouth overall accomplished what was expected, most patients responded positively (91.9%), as did their parents (93.2%).

Teenage patients and their parents were questioned about what they felt was the patient's main problem. As shown in Table 1, most teens and many of their parents felt that they had no main problem or that the problem was not related to cleft. Small numbers of patients identified appearance (13.0%) and speech (8.7%) as their main concerns. Parent and patient ratings of the main problem were not significantly different ($x^2 = 5.63, 5$ df, $p > 0.30$).

All patients were asked: “If you could change one thing about yourself, what would you change?” Nearly one-third of the sample (31.3%) stated that they would change their appearance, and others (13.7%) wanted to first change aspects of their cleft-related appearance. Few patients (4.9%) stated that they primarily desired speech change. Patients desired a variety of miscellaneous changes (intelligence, financial status, name, height), and a sizable group of patients (55.8%) did not know what they would change or desired no change.

Satisfaction with Appearance

Three-fifths (59.3%) of the patients reported being very pleased with their facial appearance (Table 2). Twenty-seven percent were somewhat or very disappointed with their facial appearance. Parents were asked whether and how often their child expressed concern about appearance. Fifty percent of the parents indicated that their children never voiced concerns about their appearance, 22% reported occasional expression of their child’s concerns, and 27% reported frequent expression of concerns.

Figure 2 shows patient satisfaction with the appearance of the cleft among patients with cleft of the lip with or without cleft palate (55.8% of the sample). Of the patients with cleft lip, 36% were less than very pleased with lip appearance and 14% expressed actual disappointment. Of the parents, 44% were less than very pleased with lip appearance and 24% expressed actual disappointment. There was no significant difference between parent- and patient-rated satisfaction with lip appearance ($x^2 = 5.52, 3$ df, $p > 0.10$).

Satisfaction with Speech

All patients and parents were asked to rate speech satisfaction and to indicate how well they are understood by others. As shown in Figure 3, patients and parents were generally very pleased with speaking ability; only 8% of patients and 7% of parents stated disappointment. There was no significant difference between parent and patient ratings of speaking ability ($x^2 = 0.9, 3$ df, $p > .80$).

Figure 4, which displays the ratings of how well the patient’s speech is understood by others, indicates that most patients and parents saw the child’s speech as highly understandable. Patient ability to be understood was seen as somewhat or very impaired by 27% of the patients and 23% of the parents. Although there is no statistical difference ($x^2 = 0.55, 2$ df, $p > 0.70$) between patient and parent ratings of how well speech is understood by others, it is of interest that three patients thought they were not understandable but that their parents did not agree.
TABLE 2 Appearance Concerns

<table>
<thead>
<tr>
<th>Patient’s Evaluation of Facial Appearance</th>
<th>Percent</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very pleased</td>
<td>59.3%</td>
<td>54</td>
</tr>
<tr>
<td>Moderately pleased</td>
<td>13.2%</td>
<td>12</td>
</tr>
<tr>
<td>Somewhat disappointed</td>
<td>18.7%</td>
<td>17</td>
</tr>
<tr>
<td>Very disappointed</td>
<td>8.8%</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>91</td>
</tr>
</tbody>
</table>

Parent-Reported Frequency of Patient Expression of Appearance Concerns

<table>
<thead>
<tr>
<th>Expression of Concerns</th>
<th>Percent</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very often expresses concerns</td>
<td>27.5%</td>
<td>25</td>
</tr>
<tr>
<td>Occasionally expresses concerns</td>
<td>22.0%</td>
<td>20</td>
</tr>
<tr>
<td>Never expresses concerns</td>
<td>50.5%</td>
<td>46</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>91</td>
</tr>
</tbody>
</table>

As shown in Table 3, nearly three quarters of the parents (72.8%) thought that their child did not have a speech problem, 18% thought that their child had a moderate problem, and 9% thought that their child had a severe speech problem.

Gender Differences

The study sample was 43% female (N = 44) and 57% male (N = 58). All satisfaction, appearance, and speech rating variables were statistically examined for gender effects. Gender did not appear to significantly influence patient satisfaction, parental perceptions, or speech pathologists' ratings.

DISCUSSION

Adolescents with cleft lip, cleft palate, or both are not generally portrayed as having dissatisfaction and unfulfilled treatment desires. Indeed, there are suggestions that their coping skills are well developed and that they develop...
high self-esteem (Brantley and Clifford, 1979). This investigation indicates that a sizable group of adolescents with cleft of the lip and palate continue to have dissatisfactions related to their cleft status and treatment. Although adolescent patients have been through a remarkably extensive course of surgical treatments, they do not uniformly experience positive outcomes. Additional study is required to examine whether there is a relationship between the number of operations and levels of satisfaction. Although the largest group of adolescent patients with cleft appear to be generally satisfied and positive about their status, it is the patients with unresolved concerns that must be a focus for additional professional attention.

The findings in this study are derived from self-disclosures in interviews conducted in a clinic. Statements of dissatisfaction or admissions of concern about treatment are less likely to be made in the context of care. Respect for professionals and intimidation by being on "clinical turf" make it likely that the findings in this study underestimate the levels of patient and parent dissatisfaction and concern. The choice of a nonprofessional person as an interviewer was based upon the desire to minimize this bias.

This study supports Richman's (1983) finding that among adolescents with cleft, appearance is more commonly the source of social adjustment problems than is speech. Almost 60% of the patients in this study were not fully pleased with their facial appearance, and more than one-third of patients with cleft lip and their parents were less than fully satisfied with the appearance of the lip. The magnitude of expressed dissatisfaction is striking and has not previously been reported. The findings suggest that some of the patients will require additional surgical, dental, or psychological treatment directed toward improving their satisfaction with appearance. The findings also suggest that there may be a limit to what surgical care can accomplish. Perhaps surgery never fully eradicates a blemish or entirely remedies personal dissatisfaction. For some patients, any scar or asymmetry can serve as a reminder of their being "different."

When speech was self-rated, more than 25% of the patients were less than fully satisfied with their ability to talk and with their intelligibility. Parents generally agreed with their children, and one out of four believed their child to have a speech problem. This corresponds to the speech pathologists' ratings that indicate 28% are less than fully intelligible and 31% have abnormal resonance (hypernasality or hyponasality).

No significant gender effects were uncovered in this study. The lack of gender effects is notable and differs from findings by Kapp (1979) and Harper and Richman (1978), which suggested that there are gender differences in dissatisfaction and unhappiness among patients with cleft.

Generalizations based upon the findings of this study are limited in at least three ways. First, the study was conducted at only one large cleft palate team-based treatment center among patients enrolled in its routine evaluation program. Replication studies at other treatment sites or at multiple sites would be helpful. Second, this study did not attempt to separate those subjects who had essentially completed the course of treatment from those who expect additional care. Future studies are planned to ex-
amine the impact of specific orthodontic and plastic surgical interventions on the self-perceptions of adolescents with cleft. Last, no attempt was made to compare the study findings to those in normal populations. Many of the questions posed in this study apply specifically to the results of cleft surgery and treatment and would not have lent themselves to comparison with normal subjects.

It is well known that adolescents tend to express many concerns about appearance, and one would expect that this would occur in both normal and cleft groups. The fact that the parents of the patients with cleft were largely in agreement with their children’s self-evaluations suggests that those ratings were realistic appraisals of treatment outcome and appearance. The authors were surprised at the uniform and high degree of agreement between patients and their parents. Although this agreement serves to validate the findings regarding satisfaction with speech and appearance, it remains unexplained. It is uncertain whether parents of adolescents without cleft would share their child’s concerns about appearance and identity; comparison studies would be useful in understanding how adolescents with cleft differ from others. The possibility exists that adolescents with cleft and their parents are able to agree and hold satisfactions and dissatisfactions in common when focusing on treatment status. Care of adolescents with cleft usually calls for the adolescent patient and parents to work together, to be mutually supportive, and to share treatment decisions.

The expressions of concern on the part of both adolescent patients and their parents suggest that cleft palate teams and health care providers need to direct attention toward the continuing and unresolved needs of this age group. This study discredits the assumption that time and treatment uniformly result in the patient’s being “out of the woods” or at a point of relative satisfaction. Adolescents who possess dissatisfactions and continue to see themselves as having problems can be identified, and treatment interventions should be considered.

Acknowledgment. The authors wish to acknowledge Dr. Rodger Dalston, Dr. Donald W. Warren, and Ms. Laura Grady for their assistance in collecting these data.

REFERENCES


APPENDIX INTERVIEW INSTRUMENT

A. Questions for Patients:

1. What do you feel is your main problem?
   (1 = Speech, 2 = Behavior, 3 = Hearing, 4 = Appearance, 5 = Other (Specify: ____) 6 = Doesn’t know/unable to evaluate, 7 = No main problem)

2. How pleased are you with the way you talk now?
   (1 = Very pleased, 2 = Moderately pleased, 3 = Somewhat disappointed, 4 = Very disappointed, 5 = Doesn’t know/unable to evaluate)

3. Do other people understand the way you talk (how understandable)?
   (1 = Very understandable, 2 = Moderately understandable, 3 = Not understandable, 4 = Does not speak, 5 = Doesn’t know/unable to evaluate)

4. How pleased are you with the appearance of your face?
   (1 = Very pleased, 2 = Moderately pleased, 3 = Somewhat disappointed, 4 = Very disappointed, 5 = Doesn’t know/unable to evaluate)

5. How many operations to the face or mouth have you had?
   (Code Number ______)

6. Overall, did the operations on your face or mouth do what you expected?
   (1 = No, 2 = Yes, 3 = Doesn’t know/unable to evaluate, 4 = Not applicable)

7. Has your lip been repaired?
   (1 = No, 2 = Yes, 3 = Doesn’t know/unable to evaluate, 4 = Not applicable)

8. If yes (to lip repair), how pleased are you with the way the lip looks now?
   (1 = Very pleased, 2 = Moderately pleased, 3 = Somewhat disappointed, 4 = Very disappointed, 5 = Doesn’t know/unable to evaluate)

9. If you could change something about yourself, what one thing would you change?
   (1 = Speech, 2 = Change or erase lip scar, 3 = Not have cleft, 4 = Unspecified appearance change, 5 = Appearance change unrelated to the cleft, 6 = Appearance change related to the cleft, 7 = Improve physical aspects, i.e., specific body area or part not cleft-related, 8 = Miscellaneous changes, i.e., of skills or clothes, 9 = Raise intelligence level, 10 = Finish with school, 11 = Different job, 12 = Personality change, 13 = Name change, 14 = Doesn’t know, 15 =
Wouldn't say, 16 = Be older, 17 = Be younger, 18 = Have more money, 19 = Other (Specify:__), 20 = No change.

B. Questions for Parents:

1. What do you feel is your child's main problem?
(1 = Speech, 2 = Behavior, 3 = Hearing, 4 = Appearance, 5 = Other (Specify:__) 6 = Doesn't know/unable to evaluate, 7 = No main problem)

2. How pleased are you with the way your child talks now?
(1 = Very pleased, 2 = Moderately pleased, 3 = Somewhat disappointed, 4 = Very disappointed, 5 = Doesn't know/unable to evaluate)

3. How understandable do you think your child's speech is to other people?
(1 = Very understandable, 2 = Moderately understandable, 3 = Not understandable, 4 = Does not speak, 5 = Doesn't know/unable to evaluate)

4. Do you think your child has a speech problem at this time? (If yes, how severe?)
(1 = Yes, severe, 2 = Yes, slight or moderate, 3 = No problem, 4 = Doesn't know/unable to evaluate)

5. Has your child ever indicated concern over his appearance? (How often?)
(1 = Yes, very often, 2 = Yes, occasionally, 3 = No, never, 4 = Doesn't know/unable to evaluate)

6. How many operations (total) has your child had?
(Code Number____)

7. How many operations to the face or mouth has your child had? (Code Number____)

8. Overall, did the face and mouth operations do what you expected?
(1 = No, 2 = Yes, 3 = Doesn't know/unable to evaluate, 4 = Not applicable)

9. Has your child's lip been repaired?
(1 = No, 2 = Yes, 3 = Doesn't know/unable to evaluate, 4 = Not applicable)

10. If yes (to lip repair), how pleased are you with the way the lip looks now?
(1 = Very pleased, 2 = Moderately pleased, 3 = Somewhat disappointed, 4 = Very disappointed, 5 = Doesn't know/unable to evaluate)