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Possessed by Parents of Cleft Children

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# ATTITUDES, CIRCUMSTANTIAL CONDITIONS, AND THE UNDERSTANDING OF TERMINOLOGY POSSESSED BY PARENTS OF CLEFT CHILDREN

By

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# ABSTRACT

# ATTITUDES, CIRCUMSTANTIAL CONDITIONS, AND THE UNDERSTANDING OF TERMINOLOGY POSSESSED BY PARENTS OF CLEFT CHILDREN

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Thirty-one respondents (mothers, fathers, or both) from a hospital clinic and private clinic completed questionnaires designed to elicit information about attitudes, circumstantial conditions, and knowledge of terminology concerning the birth and habilitation procedures of their cleft child. Responses indicated an overall high positive parental attitude. The less favorable attitudes involved feelings of guilt and hostility.

The circumstantial conditions scale was designed to assess the personal and environmental factors that impact the family affected by a cleft. Parents indicated favorable circumstantial conditions. A positive correlation was found to exist between the scores on the attitude scale and the circumstantial conditions scale.

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Parents were asked to define 10 terms relating to a child's cleft and treatment procedures. Terms referring to professionals in the habilitative process were understood better than terms which referred to surgical procedures. Overall, the parents did not have a good understanding of the terminology.

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### Introduction

The parents of a handicapped child face problems which are often difficult to surmount. Every parent wants a "normal" child. Giving birth to a child who deviates from normality is a frustration. Many parents have difficulty raising a handicapped child because of society's attitude toward the handicapped and their parents. These factors may impede the parent's capacity to develop a strong affectionate relationship with their child. Raising a handicapped child requires wisdom, skill, and parental security.

The birth of a handicapped child sets the parents off from the others. From the first day, the mother feels herself cut off from the other mothers on the obstetrical ward (Featherstone, 1980). She is not able to share in the happy conversation about birth weights, labor, and nursing without a sense of sadness. While some parents have warm protective feelings for the handicapped, others feel threatened, fearful, uncomfortable, or even repelled in their presence

(Featherstone, 1980). Most of the fear arises naturally out of the circumstances of the handicap. Some fear is generated unnecessarily by friends and professionals who want to persuade parents to behave in a certain way.

Various studies have looked at parental insecurities involved in raising a handicapped child. Winder (1958) interviewed a group of parents who met regularly for counseling. They discussed the suffering and emotional cost involved in raising a child with cerebral palsy. Some believed their marriages had suffered, some feared that they had neglected their other children. Many resented the failure of relatives, friends, or neighbors to understand and accept their child. Other parents hesitated to identify themselves and their child with a disability. Gibson (1972) wrote that she had been unable to read about retardation for the first twelve years of her son's life. The Bureau of Educational Research of the New York City Board of Education (1954) interviewed 64 parents of disabled children in the fifth through eighth grades. A majority of them revealed that strong feelings of irritation and resentment were mixed in with their love for their children.

McWilliams (1970) pointed out that the impact of having a cleft child will depend upon the ego of the parents and their ability to use various psychological coping mechanisms. Featherstone (1980) explained how a child's handicap attacks the fabric of a marriage: "It excites powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family, and it creates fertile ground for conflict" (p. 91).

All parents must face the questions of how far to protect their children, how much independence to allow, where to set limits. Parents of disabled children feel this tension even more. Of the 123 families of children who were at the Institute of Physical Medicine and Rehabilitation in New York (1957), more than 80 experienced difficulties in parent-child relationships. Some of the parents felt unable to let their children develop independence from them. Others reacted in the opposite direction and pushed their children too hard. Spock and Lerrigo (1964) reported that parents are more apt to set an impossible ideal of perfection for themselves if their child has a handicap. They feel they should never scold, never lose their tempers, and always be ready to make more sacrifices.

Despite some grim realities, most parents do find their fears diminish with time. Some parents feel angry at professionals who fail to show them that the future need not be as bleak as it looks (Featherstone, 1980). The medical profession is typically a target of parental anger. Parents complain about the manner in which their physicians present the initial diagnosis. Bennett (1974) found that few people are pleased with the way they find out about their child's handicap.

Different types of handicaps produce different reactions in the children and in the parents burdened with them. In exploring the attitudes of children in Israel, researchers found that the socioeconomic status related to attitudes toward disability (Chigier & Chigier, 1968). Children from poorer neighborhoods considered a physical disability (wheelchair necessary, amputated hand, leg in brace) worse than a cosmetic disability (obesity, facial disfigurement). On the other hand, children from more prosperous neighborhoods thought the cosmetic handicap worse than the physical.

Clifford (1969) studied 60 pairs of parents and 60 children with clefts (30 lip and palate, 17 palate only, and 13 lip only). The children had a mean age of 7.15 months. In response to questions concerning the cleft, husbands and wives significantly agreed with each other on the severity ratings of their child. Infants with more extensive clefts were seen as more active, irritable, and less pleasant in personality characteristics. The data suggest that the extent of a deformity will influence how parents view their children. Norval et al. (1964) reported that none of the families they studied were placed in the "high stress" group if their children had cleft lips only. Hill (1956) found that parents of children with cleft lips seemed to have a more favorable attitude than those parents whose children had clefts of the palate or of the lip and palate.

Despite difficult times, individual families eventually work toward their own solutions. McWilliams et al. (1984) point out that less well-integrated parents may do a fairly good job of parenting with a normal baby, but they will have greater difficulty with a handicapped child. Norval et al. (1984) conducted 51 interviews with mothers of cleft children. The data indicated that younger parents experienced greater stress with the cleft child than older parents. Overall, parents who were well-adjusted and secure seemed to cope well with a handicapped child.

As the parents of a handicapped child must make adjustments to cope with their situation, the handicapped child has the responsibility of learning to live with a disability. A disabled child suffers not only the discomfort of diagnostic and treatment procedures, but he may also miss out on some of the activities that normal children have as part of everyday life. However, requiring more physical care, a disabled child usually receives more nurturance from his mother and often from the whole family. Richardson et al. (1964) reported that parents and teachers often give the child less work to do and less responsibility to carry.

Jones and Sisk (1967) studied children's perceptions of other children's handicaps. Young children were asked questions about pairs of drawings in which one child was wearing leg braces and the other child was identical except for wearing no braces. Five-year-olds were likely to reject the drawings of the handicapped child, but younger children showed no differences in response to pictures of handicapped and normal children. The data suggest that rejection of handicapped children may be more evident in school-age children than in pre-school-age children.

Although there are some specific reactions that children have to handicaps, more general effects have been found. The self-concepts of a wide selection of handicapped children were investigated in a summer camp (Richardson et al., 1964). A group of handicapped and normal children were asked to describe themselves and others. In general, the handicapped children talked more about handicaps than did normal children. The handicapped boys discussed physical ability less than normals. Spatial location was discussed less by the handicapped. The authors proposed that these children had limited spatial experiences, being unable to move around so easily on their own and not having been taken places by adults as much as other children. Handicapped girls talked more than normal girls and more than handicapped boys about helping others. Comments of the handicapped children indicated that they had fewer interactions with people. Brantly and Clifford (1979) studied 172 adolescents between the ages of 10 and 18 (100 normal, 51 with cleft palates, and 22 obese). The authors looked at such variables as cognition, body image, and self-concept. Body image measures were clearly reduced for the obese subjects but not for the normal and cleft groups. Subjects with clefts appeared to have higher self-esteem than did normals. The authors suggested that the possibility of denial or some other mechanism might account for these feelings.

Harper and Richman (1978) administered The Minnesota Multiphasic Inventory (Hathaway & McKinley, 1951) to 46 adolescents with orthopedic problems and 52 adolescents with cleft lip and palate and mild-to-severe facial disfigurement. The authors reported both groups to be within normal limits for adolescents but found that both showed inhibition as one of their outstanding characteristics. While cleft subjects experienced anxiety, self-doubt, and discomfort regarding interpersonal relationships, the orthopedically handicapped became physically and psychologically isolated from peer interaction. MacGregory (1951) conducted a study describing 151 patients with varying degrees of facial disfigurement. She reported that the majority were upset about their appearance and that they "saw their handicaps reflected in the reaction of others toward them." The majority of patients suffered from behavior difficulties including feelings of inferiority, self-consciousness, anxiety, hyper-sensitivity and withdrawal from social activities.

Kapp (1979) published a study of self-concept in 34 children with clefts between the ages of 11 and 13. They were matched with 34 control subjects. The Piers-Harris Children's Self-Concept Scale (Piers, 1969) was administered to each child. The author found no significant difference between the cleft and control subjects on global self-concept scores. However, as a group, both males and females with clefts expressed greater dissatisfaction with personal appearance than did those without clefts. The females with clefts appeared to be significantly more anxious, less successful in school, and more unhappy and dissatisfied than the normal subjects or male cleft subjects.

Numerous studies have analyzed the personality and adjustment conflicts that confront children with clefts. In a study by Richman (1976) both the boys and girls with clefts were rated by their teachers as having significantly more internalizing behavior than their peers in the control group and in the published norms. On the other hand, Wirls (1971) concluded his literature review this way:

> In spite of the compelling theoretical basis of social and psychological maladjustment in children with cleft palate, the research results have been inconclusive. If the results tend in any direction, it is toward the absences rather than the existences of maladjustment (p. 126).

Few writers reveal definitive evidence to adequately explain the wide variance that occurs in children with clefts as they attempt to cope with their handicap.

Parents significantly influence their children's attitudes and behaviors. Children model their behavior on the behavior of people they love, people they admire, and people who seem to be powerful. Therefore, they often do what parents do and say and act like their parents (Smart & Smart, 1978). McDonald and Berlin (1979) proposed that the cleft child's emotional adjustment depends on the way the parents work out their own feeling towards it. Moffat (1961) stated that ignorance on the part of parents may lead to feelings of guilt, which later become hostility and rejection or overprotection, each of which is damaging to the child's future usefulness to society. It would appear then that a major focus of cleft habilitation must be directed toward the parents. According to Slutsky (1969), attention is typically focused on the affected child. In reality, the parents often feel themselves to be the affected ones. The professionals need to inform and help the parents understand the conditions of the cleft and the treatment procedures, since the child will turn to the parents at home for further clarification and reinforcement (MacDonald, 1979).

An element that must certainly affect how parents respond to having a child with a cleft is the manner in which they are informed about the defect and the kind of counseling and support they receive (McWilliams et al., 1984). Hill (1956) and Spriestersbach (1961, 1973) reported that parents of children with cleft lip and/or cleft palate are poorly informed. Dar, Winter, and Tol (1974) were surprised that sophisticated and educated parents expressed gross misapprehension or superstitions as to the cause of the cleft. Slutsky (1969) found that 76% of the mothers in his study had no knowledge of what a cleft was prior to the birth. Furthermore, 44% of the mothers expressed no knowledge of the possible causes of clefting at the time their child was 7 to 14 years old. The author claimed that the most impressive outcome of the extensive contact with parents in the clinic was "the revision of their attitudes toward the deformity, greater acceptance of the child's limitations, reduction of anxieties concerning the child's future, and increased cooperation in the total clinical process (Slutsky, 1969).

## Statement of the Problem

There is evidence to suggest that parents want and need more information about clefting and related problems than they are often given (Bradley, 1960). MacDonald (1979) reported that parents desired printed materials explaining the clefting condition. Parents need adequate information to reply to relatives and neighbors carrying misconceptions about the cause and results of the defects. Spriestersbach (1973) explained that the concerns of parents change over time. When the baby is born, they worry about the baby's survival, the spouses feelings, and the child's appearance. Later, speech, dental needs, and social development will become the primary concerns.

Walesky-Rainbow and Morris (1978) found that 87% of the professionals in their study encouraged the parents to provide information to their child. However, only one professional stated that he thought the parents were able to give their children accurate and sufficient information about the cleft problem.

Information is beneficial for the healthy attitude of the parent as well as the child. Barry (1965) stated that the cleft individual's willingness to participate in rehabilitative procedures is related to the patient's acceptance of his disability and his expectations about rehabilitation. Factors which may influence these considerations are what the child knows about his cleft and what facts he has about the treatment plan. Because children will often turn to the parents at home for further clarification and reinforcement, parents need to be well informed (Walesky-Rainbow & Morris, 1978).

Hill (1956) reported a positive relationship between the amount of information possessed by parents of children with clefts and the positiveness of their attitudes toward the child and his potential. There is tremendous opportunity for the acquisition of information during each routine office visit with the various professionals on a cleft palate team. Specialists tend to communicate using professional terminology that is unclear and confusing to parents. For various reasons, parents may hesitate to question or ask for clarification of the information. As a result, what seems obvious and straight forward from the professional's perspective may actually be confusing and unsettling on the part of the parents. Procedures and surgeries take place without a clear understanding by the parents or the children about what is actually happening and why. The confusion and misunderstanding undoubtedly hinders the development of positive attitudes.

A child who has a cleft lip presents a different problem from that of a child who has a cleft lip and palate. In addition, some children may be affected by other abnormalities and complications. Less extensive clefts are easier for most parents to accept (McWilliams et al., 1984). Hill (1956) reported from his interviews and objective tests of 70 parents of children with clefts that parents of children who had cleft lips gave fewer responses suggestive of rejection than did parents whose children had palatal clefts or clefts of both the lip and palate. In addition to the severity of the child's condition, parental attitudes may be influenced by the degree to which the child's deformity affects the overall family situation. Several factors which may be influenced include relationships between family members, finances, or employment.

The purpose of this study is to evaluate the following questions:

1. Are there any specific attitudes that characterize parents of cleft palate children?

2. Are there any specific circumstantial conditions that typically create difficulty for parents of cleft palate children?

3. Do parents with positive circumstantial conditions have "better" attitudes than those with more negative conditions?

4. Do parents understand the terminology used by professionals and does this understanding affect their attitudes?

# Chapter II

## Methodology

### Development of the Questionnaire

Questionnaires based on surveys from previous studies were employed to assess parental attitudes and circumstantial conditions. An additional section was designed to determine parental knowledge of terminology associated with the child's deformity. The attitude section of the questionnaire was based on a scale constructed and used in a study by Hill (1956). Hill, along with the faculty and several graduate students at The Pennsylvania State University Speech and Hearing Clinic, produced sixty-nine terms to describe the attitudes or feelings parents might have about their cleft palate children. Nine of the sixty-nine terms occurred in every sample. Three of these terms were eventually discarded because of their overlapping similarity in definition. The remaining six terms were chosen to represent the parental attitudes. For the purpose of designing a series of statements pertinent to each of the terms, Hill (1956) used the following definitions:

> Acceptance - An experience, or feature of experience or behavior characterized by a positive (approaching) attitude toward some concept or judgement.

Rejection - An experience, or element of experience characterized by a negative or antagonistic attitude with respect to some concept or judgement.

Hostility - An attitude characterized by unpleasantness, and by activity detrimental to the welfare of the individual or group toward whom the attitude is directed.

Embarrassment - An emotional condition marked by unpleasant self-consciousness, and by some degree of confusion and impulsional conflict.

Guilt - An emotional state, in which the individual is dominated by the belief or knowledge that he has contravened some social custom, ethical principle, or legal regulation.

Overprotection - A tendency to exceed the usual limits of parental control, resulting in prolongation of each stage of biosocial maturation and overtraining in immature, dependent behavior through surrounding the child with restrictions, interventions, and detailed instructions.

Hill (1956) proceeded with his colleges to construct 48 statements which conformed to the definition of each attitude. Nineteen trained judges (all members of the faculty or graduate student clinicians at The Pennsylvania State University Speech and Hearing Clinic) categorized the 48 statements into six specific attitudes. Agreement was generally high among these judges, ranging from more than 80% to unanimous agreement. The least definitive statements were eliminated. Finally, five of the most experienced clinicians at the clinic individually chose the five items in each of the six categories which they considered the most pertinent. The finalized attitude scale consisted of thirty statements selected by this final series of judgements, with each of the six attitude categories having five pertinent statements.

Unlike Hill's (1956) study, the thirty attitude questions in the present study were followed by five alternative selections including strongly agree, agree, unsure, disagree, and strongly disagree. The selections were ordered to reflect the least positive attitude (number 1) to the highest positive attitude (number 5). To randomly select the order in which the attitude statements would appear on the questionnaire, each of the 30 attitude statements was typed on a piece of paper and placed in an envelope. The envelopes were randomly drawn until all 30 envelopes were selected.

Acceptance

1. Parents of a child with a cleft should treat him like any other child.
2. I feel sure that my child will do many things which will make me feel proud.
3. Neighbors are naturally interested in other's problems, so parents should explain things to them.
4. Children with clefts can be helped to lead happy, useful lives.
5. This child has brought us much happiness.

Rejection

1. I wish my child had never been born.
2. In a way it would be better if the Lord had taken my child before he was a week old.
3. It would be better for people not to have a child if they knew it would have a cleft.
4. I'd like to send my child away some place until he would be made normal in every way.
5. I would have adopted a child if I had known mine would have a cleft.

Embarrassment

1. I seem to lose my presence of mind when people show that they know my child has a cleft.
2. When people ask me about my child I feel flustered.
3. When people ask questions about my child's cleft I feel confused and find it difficult to answer.
4. I feel self-conscious when explaining to people about clefts.
5. I feel ill-at-ease when someone talks about cleft palate and cleft lip.

Hostility

1. I feel unfriendly toward people who look at or ask about my child.
2. I resent having to explain my child's condition to people.

3. When people ask me about my child I feel angry.

4. I would like to tell the professional people who have worked with our child how much their attitudes have hurt my feelings.

5. I often wish people would mind their own business and not pry into my child's affairs.

Overprotection

1. A cleft palate child should be kept close to his parents at all times.

2. Parents of a child with a cleft should expect less of him than of other children.

3. A child with a cleft should not be punished as severely as his brothers and sisters.

4. Normal children can take care of themselves better than cleft palate children.

5. Parents should spend much more time in the home with cleft palate children than with other children.

Guilt

1. I sometimes wonder what I did to cause my child to have a cleft.

2. If I could undo some things I did before my child was born, he might not have a cleft.

3. A cleft palate child makes you wish you had done things differently.

4. I wonder whether it was my husband (or wife) or myself who caused our child to have a cleft.

5. I can't help feeling that something I did caused my child's cleft.

The circumstantial conditions portion of the questionnaire used in this study contained items designed to shed light on the personal and environmental factors that impact the family and child affected by a cleft condition. Many of these statements were similarily addressed in a study by Spriesterbach (1973). The statements were included under seven major headings.

## Financial and Professional Interests

1. The family has experienced financial sacrifices in managing the child.
2. I worry about the ability to financially support this child.
3. My employment has been stable.
4. I have had to adjust my employment status to meet the needs of my child.
5. I believe that my present employment uses and demonstrates my abilities.

## Speech-Language and Audiology

1. I understand about the speech problems of children with cleft palates.
2. I worry about what outsiders think of my child's speech.
3. I am satisfied with the speech correction therapy my child has received.
4. I understand the problems concerning hearing.
5. I was warned about the possibility of a hearing loss.

## Family Dynamics

1. The child's illnesses, including procedures for managing the cleft(s), have been upsetting to the family as a group.
2. This child was planned and desired by both parents.
3. Family and friends have accepted this child as they would any other child.
4. I am satisfied with my spouse's participation in the management of this child.
5. This child has caused tension in our marital relationship.

## Personal Beliefs

1. It is important to have other family members living in the area for support.
2. Religious convictions have been a source of comfort and stability.
3. It is important to actively participate in spare-time activities such as movies, dancing, sports, parties, trips, etc.
4. An important thing in this world is to be physically normal.
5. Having a child with a cleft has caused me to reassess my personal values.

## Information and Decision Making

1. After the child was born, I received adequate information on the characteristics of a cleft disorder and the possibilities of treatment.
2. I was left with a feeling of hope after the child's problems and treatment possibilities were first explained to me.

3. Professionals have spent sufficient time with me to explain to me about my child's condition.

4. I have been given advice which was contradictory to that which I received in the initial counseling sessions.

5. I feel parent support groups are informative and beneficial.

## Surgeries and Hospitalization

1. I am adequately informed about each surgical procedure before it occurs.

2. My child has undergone too many surgeries.

3. Surgical procedures have produced the expected results.

4. My child stays in the hospital too long after surgery.

5. Hospitalization creates an inconvenience for my family.

## Child's Adjustment

### Socialization

1. My child is upset by classmates' teasing.

2. My child has trouble making friends.

3. My child plays well with other children.

### Physical Development

1. My child finds his/her appearance disturbing.

2. My child is healthy.

3. My child's physical development is appropriate for his/her age.

Educational Development

1. My child does not perform as well academically because of the cleft and its associated problems.
2. I am pleased with the grades my child receives in school.
3. A cleft condition effects a person's mental ability.

Discipline

1. Because of the cleft, I find it harder to punish this child.
2. My child feels he/she is disciplined too harshly.
3. My child seems more disobedient than other children.

Self-Image

1. My child is happy.
2. My child has a positive self-image.
3. My child is shy around peers because of the cleft and/or its associated problems.

Each of the statements was followed by five alternative selections including strongly agree, agree, unsure, disagree, and strongly disagree. The alternative selections were ordered to reflect the most negative circumstantial condition (number 1) to the most positive circumstantial condition (number 5).

The final portion of the questionnaire included a list of 10 terms commonly used by professionals and relating to the treatment procedures or conditions of a cleft. The items were selected from an original list of 30 terms frequently used by professionals in a cleft palate clinic. Their common usage was confirmed by a plastic surgeon not associated with this cleft palate clinic. The final list of 10 words was thought to best represent terms that are commonly used by professionals.

1. Fistula
2. Pharyngeal Flap
3. Obturator
4. Hypernasality
5. Prosthodontist
6. Velopharyngeal Incompetence
7. P.E. Tubes
8. Occlusion
9. Otolaryngologist
10. Audiologist

The parents were asked to produce a definition that best represented each term. The terms were scored as follows:

0 = no definition attempted

1 = attempted definition, incorrect

2 = weak definition

3 = strong definition

If the definition page was left completely blank, a notation was made stating that there was no attempt at defining the terms. In such a case, no score was given for the definition section.

Included with the questionnaires was an information section designed to acquire additional data on the parent responding and the child for whom the questionnaire was completed. Items included specifics about the parents and his/her years of education completed, a check-list of services provided for the child, information about the child's birth, age of siblings, and other persons known to have a cleft.

## Selection of Subjects

The thirty-one subjects studied were selected from among the parents of children with clefts treated in the Mid-Michigan and Detroit areas. The terms of selection were that the subject be the parent (mother or father) who was most involved in the planning and procedures concerning the child and his/her cleft condition. The child had to be affected with a congenital cleft of (a) the palate or (b) both the lip and palate and be within the ages of 5-14. The cleft of the palate was deemed necessary to help increase the probability that some speech difficulties existed. Furthermore, the age range was specified as it relates to the ages in which a variety of surgical and treatment procedures often take place. Previous studies have reported that parental attitudes are often reflected in the degree of clefting that exists in a child. It was felt that this study related to a more severe clefting population by eliminating responses from parents with children that have only a cleft lip.

Subjects were obtained from two sources. A plastic surgeon's office in the Detroit area pulled all files of children who fit the specified criteria for this study. Thirty files were reviewed, and the parents of these children received the mailed questionnaires. Likewise, a cleft-palate clinic associated with a hospital in the Mid-Michigan area pulled all files (totaling twenty-eight children) who fit the requirements specified. The clinic was responsible for mailing the questionnaires to the parents of these children. Neither the total number of cleft patients at each clinic nor the number of patients fitting the specified criteria for this study are known.

In its final form, the questionnaires designed for this study were mailed to fifty-eight subjects. Subjects were given the following instructions:

> We ask that the questionnaires be filled out by the parent who is most involved in the planning and procedures concerning the child and his/her cleft condition. Please read each question carefully and circle the appropriate response as it relates to your child. Note that the alternatives may be in a different order for each question. Please do not consult a dictionary, other reference materials, or other people. Notice both sides of each page.

Parents were asked to return the questionnaires in the self-addressed stamped envelope provided. Parents receiving questionnaires from the plastic surgeon's office were requested to return the completed questionnaires to this same office. In the same way, parents whose children receive treatment at the clinic in Mid-Michigan returned their completed questionnaires to the clinic.

# Chapter III

## Results

Thirty-one (53%) of the mailed questionnaires were returned. Of the 30 questionnaires mailed from the private clinic, 19 (63%) were returned, while 12 (43%) of the 28 questionnaires mailed from the hospital clinic were returned. The general data about the parents and their children with clefts are summarized in Table 1.

An analysis of the general data revealed that most of the questionnaires were completed by mothers. One hundred percent of the subjects from the private clinic who reported their marital status were married, and 58% of the subjects from the hospital clinic indicated a married status. Although none of the parents from the private clinic indicated a single status, 25% of the parents from the hospital clinic indicated a single status. Some respondents from both clinics failed to indicate a married or single status.

Most of the respondents indicated a high school level of education. Parents from the private clinic

Table 1

General Data Concerning Parents and Their Children with Clefts

| | Private Clinic (n=19) | Hospital Clinic (n=12) |
|---|---|---|
| Parent Information | | |
| Mothers Responding | 79% | 100% |
| Fathers Responding | 11% | |
| Both Responding | 11% | |
| Respondents Married | 68% | 58% |
| Respondents Single | | 25% |
| Respondents Highest Ed. | | |
| Jr. High | 5% | |
| High School | 47% | 67% |
| BA/BS | 21% | 17% |
| Grad/Professional | 16% | 8% |
| Not Indicated | 16% | 8% |
| Known of a Cleft | | |
| Immediate Family | 5%* | 17% |
| Relative | 21% | 17% |
| Friend | 21% | 42% |
| Other | 26% | |
| None | 47% | 25% |
| Age of Child | | |
| 3-6 | 47% | 8% |
| 7-9 | 21% | 42% |
| 10-12 | 21% | 33% |
| 13+ | 11% | 17% |
| Place of Birth | | |
| Home | | 8% |
| Hospital | 95% | 83% |
| Unknown | 5%* | 8% |
| Order in the Family | | |
| Only Child | 21% | 17% |
| Oldest of Other Children | 21% | 33% |
| Middle Child | 16% | 33% |
| Youngest Child | 42% | 8% |
| Number of Services Provided | | |
| 3 | 0% | 8% |
| 4-5 | 11% | 17% |
| 6-7 | 68% | 58% |
| 8+ | 21% | 17% |

*These children were adopted.

who completed the questionnaires together had educational levels of BA/BS or Grad/Professional for each parent.

The respondents in this study had little previous experience with clefting in the immediate family (10%) or with relatives (20%). Thirty-nine percent of the subjects knew of friends or others with a cleft. An additional 39% had not known of anyone with a cleft prior to the birth of their child.

When developing this study, it was uncertain whether the age of the children would influence the parents' responses to the questionnaires. The private clinic had a greater percentage of children in the lowest age grouping (3-6). Both clinics had a similar number of children in the upper age groupings (10-13+). The age distribution appeared to have no effect on the final results as evidenced by similar scores from the hospital clinic and the private clinic.

## Results of the Attitude Scale

Eight-seven percent of the total respondents completed all items on the attitude scale. Four of these questionnaires were returned with 1 to 3 questions omitted. In order to compare total scores between respondents, adjustments had to be made for those who did not respond to all the questions. Data manipulation consisted of determining the average response score and multiplying it by the number of questions omitted. This number was rounded off to the nearest whole number, and a new total was obtained. The mean score on the attitude scale from the private clinic totaled 136.20. The mean score from the hospital clinic was 128.50 (see Table 2).

Table 2

Scores on the Attitude Scale

| | Private Clinic | Hospital Clinic | Combined |
|---|---|---|---|
| Mean | 136.2 | 128.5 | 133.3 |
| Standard Deviation | 11.0 | 9.1 | 10.9 |
| Average Response | 4.5 | 4.3 | 4.4 |

An analysis was conducted to determine the percentage that each of the five alternatives were selected on the entire Attitude Scale. Results from the 926 total responses indicated that 89% were in the 'more favorable' region of the attitude scale (scores of 4 and 5). A score of 3 (indicating uncertainty) was included with the less favorable region of the scale (scores of 1 and 2) because the attitude questions were worded in such a way that the 'unsure' response reflected a less positive attitude rather than a neutral position as might be expected. Eleven percent of the responses fell within these 3 categories.

A further analysis was conducted to determine which items had a consistently greater number of responses at the 'less favorable' end of the scale (scores of 1 to 3). For the six attitude subgroups, the responses falling into the less favorable region of the scale were as follows: guilt (40%), hostility (28%), embarrassment (11%), overprotection (10%), acceptance (7%), and rejection (4%).

## Results of the Circumstantial Conditions Scale

Seventy-four percent of the respondents completed all items on the Circumstantial Conditions Scale. Eight of these questionnaires were returned with 1 to 4 questions omitted. One respondent omitted 6 questions. To allow for score comparison, data were manipulated as described for the Attitude Scale. The mean score on the Circumstantial Conditions Scale from the private clinic totaled 184.70. The mean score from the hospital clinic was 170.60 (see Table 3).

Table 3

Scores on the Circumstantial Conditions Scale

| | Private Clinic | Hospital Clinic | Combined |
|---|---|---|---|
| Mean | 184.7 | 170.6 | 179.3 |
| Standard Deviation | 11.7 | 20.4 | 16.8 |
| Average Response | 4.1 | 3.8 | 4.0 |

An analysis was conducted to determine the percentage that each of the five alternatives were selected on the Circumstantial Conditions Scale. Of the 1,387 responses circled on the Circumstantial Conditions Scale, results showed that 80% of the respondents indicated favorable circumstantial conditions (scores of 4 and 5). Questions drawing the highest percentage of these scores included:

1. I understand about the speech problems of children with cleft palate.
2. Family and friends have accepted this child as they would any other child.
3. My child is happy.

It was felt that the response of 3 (unsure) indicated a more neutral position on this scale as opposed to the attitude scale. Forty-five percent of the total responses scored as 3 (unsure) pertained to the specific question about the informative and beneficial nature of parent support groups. Questions drawing the highest percentage of scores in the 1 and 2 range included the following:

1. It is important to have other family members living in the area for support (46%).
2. Hospitalization creates an inconvenience for my family (42%).
3. Having a child with a cleft has caused me to reassess my personal values (32%).

Twenty-nine percent indicated that their child was upset by classmates' teasing. Twenty-six percent of the families experienced financial sacrifices in managing the child and felt that the child's illness, including procedures for managing the cleft, were upsetting to the family as a group. Twenty-six percent of the respondents felt they had not received adequate information on the characteristics of a cleft disorder and the possibilities of treatment. Twenty-six percent also felt they had been given advice which was contradictory to that which was received in the initial counseling sessions. Unlike the attitude questionnaire, the above items were dispersed across the 7 categories.

The private clinic was noted to have higher mean scores than the hospital clinic on both the Attitude and Circumstantial Conditions Scales. A t-Test indicated that these differences were not statistically significant at the .05 level of confidence. Therefore, the attitude scores from both clinics were combined and correlated with their corresponding circumstantial conditions scores using a Pearson product moment correlation. A correlation (*r*=.73) was found to exist between the scores obtained on these two scales. This was statistically significant as it exceeds the .005 confidence interval. These data suggest a positive relationship between a family's circumstantial conditions and the attitudes they uphold.

## Terminology

Eighty-seven percent of the respondents made an attempt to define the terms as evidenced by written material on the terminology page. It is unknown whether the remaining 13% chose not to complete this portion of the questionnaire or unknowingly missed this last page. (Directions specified that questions appeared on both sides of each page.) Scores were determined by the author's comparison of the definitions with standard textbook definitions based on the scale found in Table 4. There was a total of 30 points possible for this section (10 terms worth 3 points each). The combined scores ranged from 3 to 30 points, with a mean of 17.10 and a standard deviation of 8.30.

Certain terms were understood better than others. At least 50% of the respondents correctly defined

Table 4

Distribution of Terminology Scores

| | 0<br>No<br>Answer | 1<br>Incorrect<br>Answer | 2<br>Weak<br>Answer | 3<br>Strong<br>Answer |
|---|---|---|---|---|
| Fistula | 48% | 19% | 4% | 30% |
| Pharyngeal Flap | 19% | 4% | 55% | 22% |
| Obturator | 55% | | 19% | 26% |
| Hypernasality | 19% | | 15% | 66% |
| Prosthodontist | 26% | | 4% | 70% |
| Velopharyngeal Incompetence | 63% | 4% | 15% | 19% |
| P.E. Tubes | 19% | | 31% | 50% |
| Occlusion | 55% | 7% | 7% | 30% |
| Otolaryngolist | 33% | 7% | 11% | 48% |
| Audiologist | 7% | 4% | 4% | 85% |
| Average Percent | 34% | 5% | 16% | 45% |

hypernasality, prosthodontist, P.E. tubes, otolargygologist, and audiologist. At least 55% of the respondents wrote nothing or incorrectly defined the following terms: fistula, obturator, velopharyngeal incompetence, and occlusion. Pharyngeal flap received the highest percentage of 'weak' definitions. A t-Test revealed no significant difference between the two clinics on the definition scores. Although respondents were asked to define the terms without the assistance of reference materials, it was suspected, based on the complexity of their definitions, that some respondents did make use of reference materials. Because of a lack of certainty over the respondents' actual knowledge and the overall pattern of low terminology scores, a formal correlation analysis between the definition scores and the attitude or circumstantial conditions scores was not attempted. Overall low terminology scores would seem to indicate a lack of understanding about certain procedures associated with the child's condition. Because of such low scores and uncertainty about the validity of the definitions, a correlation analysis between the terminology scores and the attitude or circumstantial conditions scores was not attempted.

# Chapter IV

## Discussion, Summary, and Conclusions

### Discussion

An analysis of the general data revealed that most of the questionnaires were completed by mothers. This indicates that mothers are typically the parent primarily responsible for the child's treatment. Thirty-nine percent of the parents in this study had little prior experience with clefting in the immediate family or with relatives. Hill (1956) found that 47% of the subjects in his study had never seen a person with a cleft.

The children from the private clinic were younger in age than the children from the hospital clinic. Although there was no statistically significant difference in mean attitude scores between the two clinics, this study indicated that the respondents with younger children showed a slightly higher mean attitude score. On the other hand, Hill (1956) reported that parents of children in the later stages of treatment were less likely to suggest rejection and poor attitudes.

Subjects in this study appeared to have very healthy attitudes as suggested by a high percentage of positive responses on the attitude scale. Perhaps the attitude scale used in this study was not sensitive enough. However, the positive attitudes coincide with results of previous studies. Hill (1956) developed the attitude scale used in the current study. Rather than including a 5-point scale for the responses, he requested a yes/no response to each of the questions. Hill reported a high percentage of favorable responses to the attitude questions. He speculated that this high percentage may have occurred because the items were not discriminative enough. Numerous studies support the idea that most parents come to terms with the deformity and handle the stress involved as they would handle stress in general (Clifford, 1969; Slutsky, 1969; Tisza & Gumpertz, 1962; & McWilliams, 1984).

The majority of 'less favorable' responses were indicated for the questions concerning guilt and hostility. Hill (1956) also found guilt to be a recognized difficulty along with overprotection. Noval et al. (1964) reported from their interviews of mothers with cleft children that the highest stress factor was the initial experience of guilt by both parents. Spriestersbach (1973), Bradley (1960), and Moffat

(1961) all reported parental feelings of guilt involving the birth of a cleft child.

The questions concerning hostility involved the reactions of parents towards other people who respond to the child's deformity. Slutsky (1969) indicated in his study that mothers reported anxieties about others' reactions, and many mothers felt that others' reactions hindered the acceptance process. Castellanos and Stewart (1964) also reported that parents of cleft palate children tended to avoid social contacts because of the appearance of their child and others' reactions to the child.

According to the present study, parents feel their circumstantial conditions are rather positive. An obvious negative circumstantial condition concerning the inconvenience of hospitalization was indicated by 42% of the subjects. Forty-five percent of the respondents were 'unsure' about the benefit of parent support groups. Some questioned whether support groups existed. It is uncertain whether the other respondents attended such a group and were unsure about their helpfulness or whether they knew of such a group but chose not to participate. Pannbacker et al. (1979) concluded from their study that parent support groups served a useful purpose in providing parents with information about the cleft condition. Such a group can provide an environment for parents to ask questions and share experiences with others who can relate to the emotional and stressful factors associated with raising a cleft child. Researchers and professionals need to further investigate the benefit of parent support groups.

Most of the questions in the circumstantial conditions section clearly implied a positive or negative condition. However, it is felt that other questions were not worded correctly to imply a positive or negative situation. Such questions were listed under the 'personal beliefs' subgroup. For example, 46% of the subjects felt that it was not important to have other family members living in the area for support. It is not certain whether these parents even have family members living in the area to know what support may be given. On the other hand, these respondents may have family living in the area, but the family is not supportive or their support is not welcomed. Nevertheless, the responses to this question indicated that other family members were not turned to for support. Perhaps the support needs to come from professionals who are directly involved in the care and treatment of the child.

In another example, 32% of the parents did not reassess personal values following the birth of their cleft child. Previous studies (Featherstone, 1980;

Bradley, 1960; & Slutsky, 1969) reported that the birth of a handicapped child caused parents to reassess personal beliefs about the importance of life and the value of human relationships. However, it cannot be assumed from the subjects in this study that negative attitudes existed before the birth of their child. Perhaps these parents highly regarded life and human relationships so that adjustments were not necessary.

Approximately one quarter of the respondents felt they had not received adequate information about the characteristics of a cleft disorder and the possibilities of treatment. They also felt they had been given advice which was contradictory to that received in the initial counseling sessions. These data coincide with numerous studies supporting the idea of parents wanting and needing more information about their children's condition (Pannbacker, 1968; MacDonald, 1979; Slutsky, 1969; & Walesky-Rainbow & Morris, 1978). It is the professionals' responsibility to supply the necessary written material and verbal information about the child's deformity and various surgical procedures. It is also the parents' responsibility to read and pursue the information, ask the necessary questions, and attend informative and supportive groups where they may share or acquire knowledge.

The original plan of analysis for the terminology section involved a comparison of the parents' answers with a list of definitions compiled by speech-language pathologists, a physician, and a textbook. After receiving the completed questionnaires, it became apparent that such a comparison could not be made. In addition to using vague descriptive language, the subjects failed to define 34% of the terms. Furthermore, it is uncertain whether some of the subjects used reference materials to assist in defining the terms. It was apparent that the best-defined terms related to professionals whom the parents interacted with in pursuing treatment for their child. The terms which were not well-understood referred to specific procedures or characteristics directly related to the child's condition or treatment. This confirmed the original hypothesis indicating that commonly used terminology was not explained to the parents. This indicated a need for more informative communication between professionals and parents.

## Summary

Thirty-one respondents (mothers, fathers, or both) completed questionnaires designed to elicit information about attitudes, circumstantial conditions, and knowledge of terminology concerning the birth and habilitation procedures of a cleft palate/lip and palate child. The attitude questionnaire included questions that related to feelings of guilt, overprotection, embarrassment, hostility, acceptance, and rejection. Responses indicated an overall high positive parental attitude. Forty percent of the 'less favorable' attitudes involved feelings of guilt and 20% involved feelings of hostility.

Responses to the circumstantial conditions questionnaire also indicated rather favorable conditions for these families. Despite the fact that most of these children were involved with 6 to 8 different professional services, the parents did not indicate that the conditions were unfavorable. More than 25% of the respondents indicated that (1) hospitalization created an inconvenience for the family. (2) the family experienced financial sacrifices in managing the child, (3) the child was upset by classmates' teasing, (4) the child's illnesses and procedures for managing the cleft were upsetting to the family as a group, (5) adequate information about the disorder and treatment was not given following the child's birth, and (6) contradictory advice was given since the child's birth. Forty-five percent of the subjects were 'unsure' about the benefit of parent support groups.

Terminology concerning the child's disorder and treatment procedures was generally not well-understood by the parents. Those terms which referred to specific professionals were understood better than terms which referred to surgical procedures used in the habilitation process. This indicated a need for better communication between parents and professionals regarding the management of a cleft disorder.

## Conclusions, Comments, and Suggestions for Future Research

The present study was designed to evaluate the following questions:

1. Are there any specific attitudes that characterize parents of cleft palate children?

On the basis of this investigation, it may be concluded that parents of cleft children adjust and maintain positive attitudes with some feelings of guilt and hostility. It is felt that the attitude scale used in this study was highly effective in assessing a variety of feelings that parents might possess related to their cleft child. Future research might focus on the parental feelings of guilt and hostility to determine the basis of such attitudes. Perhaps feelings of guilt may be alleviated with more information and communication about the causes of clefting.

2. Are there any specific circumstantial conditions that typically create difficulty for parents of cleft palate children?

Hospitalization, financial responsibilities, and procedures for managing the cleft are upsetting for many families. Some parents felt they were not adequately informed about the deformity and treatment procedures. It is suggested that some changes be made with the Circumstantial Conditions Scale to improve the clarity of the questions and to make the positive or negative connotations more obvious. Additional research needs to take an in-depth look at the structure of parental support groups and to investigate what they have to offer for parents of cleft children.

3. Do parents with positive circumstantial conditions have "better" attitudes than those with more negative conditions?

A positive relationship existed between the family's circumstantial conditions and their attitudes concerning the cleft. Overall attitudes and circumstantial conditions were positive for parents of cleft children in this study. There is now a need to move forward and focus on the factors that create the negative attitudes of guilt and hostility and the more negative circumstantial conditions.

4. Do parents understand the terminology used by professionals and does this understanding affect their attitudes?

Parents do not seem to understand the professional terminology relating to surgical procedures in the treatment program. A lack of understanding about the disorder or treatment procedures may contribute to the negative feelings of guilt and hostility. There is a need for better communication between parents and professionals. Professionals need to provide parents and children with informative and graphic materials about the cleft and the treatment procedures. They need to provide an atmosphere where parents feel free to ask questions and to discuss the child's habilitation program. Better communication between professionals and parents is necessary to create a brighter future for the parents and children affected by a cleft.

# Appendix

## Informed Consent Letter

## Informed Consent Letter

You are asked to participate in a scientific research study being conducted in the Department of Audiology and Speech Sciences at Michigan State University. We ask that you be the parent who is most involved in the planning and procedures concerning your child with a cleft condition. You will be requested to answer 2 questionnaires about attitudes and circumstantial conditions that may influence the parents of a cleft palate child. You will also be asked to define 10 terms concerning clefting. These terms are commonly used by professionals but not always explained by them. We ask that the terms be defined without assistance from a dictionary, other reference materials, or other people.

Your participation is entirely voluntary. You are free to discontinue your participation in the study at any time, and there will be no penalty for withdrawal. Results will be treated in strict confidence, and you will remain anonymous. Within these restrictions, general results will be available to you and may be presented at professional meetings or appear in appropriate journals or other publications.

Please do not sign your name or identify yourself in any way on any portion of the information. Your confirmed consent will be indicated by your return of the completed questionnaires. Your decision to participate or not will have absolutely no effect on the treatment your child has received or will receive.

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