

Parent Responsibility in Cleft Palate Habilitation

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The role of the parent in cleft palate habilitation is an important one. A review of the literature indicates widespread agreement among workers in cleft palate habilitation that parents of children with clefts must assume an active role in the child's habilitation. Bloomer (1) regards parents as key members of the treatment group and considers success in habilitation to depend as much on parental participation as on specialized habilitation techniques. In citing the need for a total approach in the treatment of clefts, Holdsworth (5) also recognizes the value of parents as team participants. The importance of parent-team cooperation and the relationship of effective parental participation to habilitation success are also stressed by Lillywhite (6) and by Lindgren and his associates (7). Not only is it necessary that parents participate effectively in the habilitation process but, as Wright (12) has pointed out, it is highly important that they participate actively from the beginning. Many parents encounter difficulty, however, in functioning as members of the cleft palate team. In some cases, these parents are not sufficiently aware of the ways in which they can contribute to the success of the child's treatment program while, in other cases, there are factors which prevent them from carrying out their responsibilities. McDonald (8, 9) has noted, for example, that the multitude of problems involved in cleft palate habilitation may leave parents bewildered and unable to function effectively as members of the team.

The urgent need for additional knowledge concerning the areas in which parents of children with clefts need guidance has been stressed in a report issued by the American Speech and Hearing Association (4). The report also directed attention to the dearth of research bearing on

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this problem. Chenoweth (3) also has called attention to the need for a better understanding of the problems and procedures involved in cleft palate habilitation and has stressed the difficulties faced by parents of children with clefts and by team members who are attempting to assist and guide these parents in the management of their children's problems.

Purpose of the Study

Although the need to assist parents of children with clefts in becoming more effective participants in the habilitation process has long been recognized, no systematic investigation has been conducted in any attempt to facilitate parental participation. The purpose of this study was to identify areas of parental responsibility in the team approach to cleft palate habilitation and to isolate factors which might play a role in impeding effective parental participation.

Procedure

DESCRIPTION AND SELECTION OF SAMPLE. This study was carried out by means of a questionnaire survey of twenty-six selected cleft palate teams. These teams were selected by three leading authorities in cleft palate habilitation, all of whom are past presidents of the American Cleft Palate Association. Since the aim was to obtain data from respondents having sufficient depth and breadth of experience to enable them to provide the information sought, it was decided to survey a purposive sample rather than a random sample of cleft palate teams. The situation here is analogous to that described by Selltiz and her associates (11) in which a group of medical specialists may be called in for consultation on a difficult case. These specialists, constituting a purposive sample, are not called in to get an average opinion of the entire medical profession. Instead they are consulted precisely because of their special experience and knowledge. The twenty-six teams selected for inclusion in this study were listed in the annual membership *Directory* of the American Cleft Palate Association. Of the twenty-six teams, sixteen were recommended by two out of the three respondents. The team recommendations made by the three authorities were arrived at independently.

CONSTRUCTION AND DISTRIBUTION OF THE QUESTIONNAIRE. Questionnaire content was developed in consultation with members of the Mount Sinai Hospital Cleft Palate Center and was refined through a pilot study conducted in five New York City cleft palate centers. Separate questionnaires were prepared for each of the following team specialists: a) coordinator, b) surgeon, c) orthodontist, d) prosthodontist, e) otolaryngologist, f) psychologist or social worker, and g) speech pathologist or audiologist.

Each questionnaire was designed to investigate a number of areas of parental responsibility hypothesized to be important from the particular

specialist's point of view, and to determine the factors which might account for parental difficulty in each area of responsibility. The seven questionnaires contained a total of 56 hypothesized areas of parental responsibility.

Under each area of parental responsibility, a list of factors thought to *impede* effective parental participation was presented. Respondents were asked to check those factors which they considered important and to identify any other factors not included in the list. Spaces were also provided for respondents to indicate whether they considered the hypothesized areas of parental responsibility to be important and whether they considered the areas to be well-managed by parents at their centers. In addition, they were asked to identify any additional areas of parental responsibility not included in the questionnaire, as well as factors considered as contributing to parental difficulty in the areas suggested.

On March 4, 1966, the questionnaires were mailed to the coordinators of the twenty-six selected cleft palate teams. By July 11, 1966, the cut-off date for responses to the study, a total of eighteen teams had responded. All of the coordinators of the eighteen teams returned their questionnaires. The number of team specialists responding were as follows: sixteen surgeons, fourteen orthodontists, thirteen speech pathologists or audiologists, twelve prosthodontists, and twelve social workers or psychologists. Thus, responses from 97 members of a total of eighteen were available for analysis.

Results and Discussion

AREAS OF PARENTAL RESPONSIBILITY. Since the specific problems and procedures involved in cleft palate habilitation were expected to vary from one discipline to another, separate questionnaires were designed for the various specialists. Examples of the hypothesized areas of parental responsibility contained in each specialist's questionnaire follow. *Coordinators:* reporting child's behavior problems; reporting child's expressed concerns about speech and appearance; consulting team regarding all aspects of child's care and treatment; understanding that results at a given time are not final. *Surgeons:* keeping surgical appointments; understanding reasons for secondary palatal surgery; carrying out pre- and postoperative recommendations. *Otolaryngologists:* prompt reporting of suspected hearing problems; protecting child from common colds; accepting conservative tonsillectomy as opposed to routine tonsillectomy. *Orthodontists:* reporting loss or breakage of orthodontic appliances; carrying out orthodontic recommendations; keeping orthodontic appointments; consulting team before permitting outside dental procedures. *Prosthodontists:* cooperating in child's oral hygiene program; encouraging child to wear prosthetic appliance; carrying out prosthodontic recommendations. *Speech pathologists:* participating actively in child's home speech program; keeping appointments for speech therapy and for

periodic speech and hearing evaluations; protecting child's hearing for proper speech development. *Psychologists and/or social workers*: willingness to become personally involved in psychological or social service programs; reporting behavior problems observed by parent or reported by others; carrying out psychologist's or social worker's recommendations.

Analysis of the data obtained revealed considerable duplication and overlapping among the various areas of parental responsibility. For this reason, it was decided to re-analyze the questionnaire data to reflect the opinions of the 97 respondents without regard to their particular professional disciplines. As a result of this analysis, it was found that the 56 hypothesized areas of parental responsibility could be classified into the following five broad categories: a) keeping appointments; b) carrying out team recommendations; c) prompt reporting of problems encountered; d) consulting team throughout the child's habilitation; and e) assuming an active role in the child's habilitation.

The data obtained regarding these five broad areas of parental responsibility are summarized in Table 1.

Table 1 presents, in percentages, the extent to which the respondents considered each area to be an important one and the extent to which each area was reported by them as presenting difficulty to parents at their centers. Table 1 also shows the range of reported frequency of parental difficulty in each area, as reported by the various groups of specialists.

As can be seen, there was virtually unanimous agreement concerning the importance of each of the hypothesized areas of parental responsibility. There was some variation, however, concerning the extent to which particular areas were reported as presenting difficulty to parents:

1. *Consulting team during child's habilitation.* Only 47% of the coordinators reported that parents fail to consult the team before permitting outside treatment. However, 67% of the prosthodontists and 71% of the orthodontists considered this area as constituting a problem. The difference between coordinators and the dental specialists seems to center

TABLE 1. Areas of parental responsibility reported by 97 cleft palate specialists.

<i>areas of parental responsibility (in order of reported parental difficulty)</i>	<i>considered important by (%)</i>	<i>parental difficulty reported by (%)</i>	<i>range of reported parental difficulty (%)</i>
consulting team during child's habilitation	93	64	47-71
keeping appointments	97	75	69-93
carrying out team's recommendations	97	75	62-85
reporting problems encountered	97	80	47-87
assuming active role in child's habilitation	98	81	75-83

around the specific nature of the outside treatment. Where the outside treatment involves any kind of dental procedure, prosthodontists and orthodontists seem to be of the opinion that definite problems may arise through the failure of parents to consult the team.

2. *Keeping appointments.* Regardless of the specialty involved, keeping appointments constitutes a problem for parents. The extent to which parents have difficulty in this area can be seen from the frequency with which this is reported as a problem. This ranges from 69% of the speech pathologists or audiologists to 93% of the orthodontists.

3. *Carrying out team recommendations.* All specialties reported parental difficulties in the carrying out of team recommendations, varying from 62% of the surgeons to 85% of the speech pathologists or audiologists.

4. *Prompt reporting of problems encountered.* It would seem that the reporting of some problems presents greater difficulty to parents than the reporting of other problems. For example, fewer than half of the coordinators reported parental difficulty in the reporting of feeding problems. However, the reporting of the child's expressed concerns about his speech and appearance was seen by over 65% of the coordinators, social workers, and psychologists as presenting difficulty for parents. The reporting of behavior problems was viewed as presenting difficulty for parents by 67% of the social workers or psychologists and by 87% of the coordinators. Three-fourths of the otolaryngologists indicated parental difficulty in the prompt reporting of suspected hearing problems. The prompt reporting of breakage or loss of the child's orthodontic or prosthetic appliance seems to be an especially prevalent problem, as it was reported by approximately 85% of the specialists concerned.

5. *Assuming an active role in the child's habilitation.* Although parents may be cooperative in other respects, there seems to be rather widespread difficulty in getting parents to take an active role in the child's speech program and in involving themselves in the center's socio-psychological services. Over 75% of the speech pathologists or audiologists and 83% of the social workers or psychologists considered this area as a problem for parents.

FACTORS CONTRIBUTING TO PARENTAL DIFFICULTY. Table 2 presents data concerning the various factors cited by respondents as impeding effective parental participation. The extent to which each factor contributes to parental difficulty is shown in terms of the number of parental responsibility areas in which each factor appeared among the first, second, and third most frequently cited contributing factors.

FACTORS CONTRIBUTING TO DIFFICULTY IN NUMEROUS AREAS. It is apparent from Table 2 that three factors stand out as impeding effective parental participation in cleft palate habilitation: a) parental difficulty in understanding habilitation problems and procedures, b) parental level of intelligence, and c) parental emotional factors. Parental difficulty in understanding habilitation problems and procedures was among

TABLE 2. Number of parental responsibility areas in which each factor appeared among the 1st, 2nd, or 3rd most frequently cited contributing factors (total number of parental responsibility areas, 56).

<i>factor</i>	<i>number of areas in which factor was cited</i>			
	<i>1st in frequency</i>	<i>2nd in frequency</i>	<i>3rd in frequency</i>	<i>1st, 2nd or 3rd</i>
failure to understand	32	12	7	51
parental intelligence	12	19	10	41
emotional factors	4	10	12	26
conflicting demands	2	5	6	13
parental indifference	1	3	6	10
conflicting advice	2	1	5	8
travel distance	1	4	3	8
comparison with another child	0	1	1	2
unawareness of child's problem	1	0	1	2
premature satisfaction	0	1	1	2
difficulty communicating	0	0	1	1
impatience with progress	0	0	1	1
inability to recognize limits of therapy	1	0	0	1
parental unwillingness	0	0	1	1
conflict with school attendance	0	0	1	1

the three most frequently cited contributing factors in 51 of the 56 areas of parental responsibility. Parental level of intelligence was among the three most frequently cited contributing factors in 41 areas. Parental emotional factors were among the three most frequently cited factors in 26 areas.

Additional factors contributing to parental difficulty in a number of areas were: conflicting demands (appearing among the three most frequently cited factors in 13 areas); parental indifference (cited in 10 areas); conflicting advice (cited in 8 areas); and travel distance (cited in 8 areas).

These seven factors were reported as impeding parental participation in all of the following areas of parental responsibility: a) keeping appointments; b) assuming an active role in the child's habilitation; c) asking questions of the team concerning child's habilitation; d) reporting problems encountered; e) communicating to the child their acceptance of his habilitation program; f) carrying out team recommendations; and g) accepting the child with a cleft and treating him like other children.

FACTORS CONTRIBUTING TO DIFFICULTY IN SPECIFIC AREAS. As seen in Table 2, factors were also identified which seem to be relatively specific in their effects in that they were reported as contributing to parental difficulty in only one or two areas. These factors are: a) comparison with another child; b) unawareness of hygiene problem; c) pre-

mature satisfaction with the child's habilitation; d) difficulty communicating with authority figures; e) impatience with progress of treatment; f) inability to recognize limits of therapy; g) parental unwillingness to become involved; and h) conflict with child's school attendance.

Comparison with another child was reported as contributing to parental difficulty in understanding why secondary surgery or prosthetic closure may be needed to improve the child's speech. Unawareness of child's problem was cited as contributing to difficulty in the areas of carrying out recommendations regarding oral hygiene and in the prompt reporting of hearing impairments. Premature satisfaction with the child's habilitation was reported as a factor in failing to carry out team recommendations. Difficulty communicating with authority figures was regarded as interfering with reporting to the team the child's problems and concerns. Impatience with progress in treatment was cited as a factor in the disruption of the child's speech therapy. Inability to recognize the limits of speech therapy was reported as contributing to parental difficulty in accepting recommendations for secondary surgery or prosthetic closure in order to make possible further improvement in the child's speech. Unwillingness to become involved was cited as an important factor in parental failure to follow through on referrals for psychological services. Conflict with school attendance was reported as interfering with the keeping of appointments.

In summary, the five factors cited most frequently as contributing to parental difficulty in the habilitation process were as follows: a) inadequate parental understanding of habilitation problems and procedures; b) parental level of intelligence; c) emotional factors (anxiety, hostility, ambivalence, guilt, bewilderment); d) conflicting demands (other parental responsibilities); and e) parental indifference.

Although, in the opinion of the respondents, these factors play the most prominent role in interfering with effective parental participation, it should be noted that the respondents' judgments concerning these factors were based on subjective opinions rather than on objective psychological tests of intelligence, personality, and attitudes. The high degree of agreement, however, among the respondents—whose judgments were arrived at independently—suggests that fairly reliable conclusions may be drawn from the data presented. In particular, it appears reasonable to conclude that efforts aimed at helping parents function more effectively in their children's habilitation must be based on a consideration of factors which are of a cognitive, affective, and situational nature. It is important, for example, to recognize the need for developing more adequate communication between parents and team. In her study of parents of children with clefts, Bradley (2) found that none of the parents in her study had an adequate understanding of even five of the most commonly encountered problems in cleft palate habilitation. The present study suggests that it is necessary to insure not only that the

problems and procedures involved in cleft palate habilitation are carefully explained to parents and that ambiguity and technical terminology be avoided in interpreting team recommendations, but that consideration also be given to parental level of intelligence in each particular case. For some parents, detailed and comprehensive explanations may be desirable but, in other cases, explanations need to be simplified, frequently repeated, and presented in relatively short units which can be readily absorbed. It is also important to recognize the extent to which feelings of guilt, anxiety, or bewilderment can render parents incapable of functioning effectively. As Ruess (10) has pointed out, parents' emotions and attitudes toward the child's defect can play a significant role in the development of the child's self-concept which, in turn, can foster or hinder the child's habilitation. Similarly, situational factors such as conflicting demands and travel distance must be dealt with in a constructive fashion by cleft palate centers if broken appointments and failure to follow team recommendations are to be reduced.

An outgrowth of this study has been the formulation of guidelines for cleft palate teams in developing in-service team and parent-education programs. These guidelines have been incorporated into parent and team manuals which are currently in process of publication.

Summary

A questionnaire survey of selected cleft palate teams was conducted to identify areas of parental responsibility in the team approach to cleft palate habilitation and to isolate factors which might play a role in impeding effective parental participation. It was found that the 56 specific areas of parental responsibility hypothesized in this study could be classified into the following five broad categories: a) keeping of appointments; b) carrying out team recommendations; c) prompt reporting of problems encountered; d) consulting team throughout the child's habilitation; and e) assuming an active role in the child's habilitation. The five factors cited most frequently as contributing to parental difficulty in the habilitation process were found to be: a) inadequate parental understanding of habilitation problems and procedures; b) parental level of intelligence; c) emotional factors; d) conflicting demands; and e) parental indifference. It was concluded, therefore, that efforts aimed at helping parents of children with clefts to function more effectively in the habilitation process must be based on a consideration of factors which are of a cognitive, affective, and situational nature. This study has led to the development of guidelines and manuals for the use of cleft palate teams in developing in-service team and parent-education programs.

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