Information and Experience with Cleft Palate: Students, Parents, Professionals

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More than 1,200 *students*, *parents*, and *professionals* completed a *questionnaire* designed to assess knowledge and experience with *cleft palate*. *Professionals* knew more about cleft palate and had had more experience with it than either parents or students. *Parents*, however, knew more about cleft palate and had had more experience with it than had *students*. There was also an apparent relationship between knowledge and experience because those who knew more about cleft palate had also had more experience and training. The results reemphasize the need for pre-professional and continuing-education programs.

Introduction

Public and professional education about cleft palate habilitation is vital. Ortiz-Monasterio (1975) has stated:

> Educating the public is quite important. Deformities are viewed more rationally when they are properly explained, and when the possibilities for treatment are outlined. Information about the centers available for treatment should also prove helpful.

Because parents play an important role in cleft palate habilitation, it is important that they be provided with the kind of information Ortiz-Monasterio suggested. Both parents and professionals have been hindered by inadequate information.

Hill (1955), Pannbacker (1977), and Spriestersbach (1961, 1973) reported that parents of children with cleft lip and/or palate are poorly informed. Dar, Winter, and Yal (1974) were " . . . impressed with the fact that sophisticated or educated parents expressed gross misapprehension or superstitions as to the cause of the cleft." The studies of Tretsven (1965) and Crocker and Crocker (1970) indicated that both the general public and parents have inadequate knowledge, including superstitions and folk beliefs. Van Demark and Van Demark (1970) found that young cleft palate adults were "startlingly ill-informed" about cleft palate. Lass and associates (1973) reported that medical and dental students at West Virginia University were also deficient in basic information about cleft palate and its associated problems.

A basic step in planning parent and professional education programs is the identification of educational needs. In an attempt to define these needs, a questionnaire was designed to assess basic information and experience with cleft palate. The twenty item questionnaire has been described elsewhere in detail (Lass *et al.*, 1973).

The Questionnaire

The questionnaire consists of a variety of types of questions, including multiple-choice, true-false, and short essays (see the Appendix). Information covered in the questionnaire include the following: (1) definitions of *cleft palate*, *submucous cleft palate*, and *pharyngeal flap*; (2) the incidence of cleft palate in the United States; (3) racial and sex differences; (4) the

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presence of language, hearing, and psychological problems; (5) reasons for secondary surgical procedures; (6) specialists who should be included as members of the cleft palate team; and (7) information on exposure to cleft palate through coursework, outside readings, and clinical experiences. The standards for scoring the items on the questionnaire came from research reported in the literature and are presented in the Appendix (Koepp-Baker, 1971; Powers, 1973; Spriestersbach and Sherman, 1968; Wells, 1971).

Subjects and Procedure

More than 1200 students, professionals, and parents of children with cleft lip and/or palate completed the questionnaire (Table 1), which was directed to three professional groups: (1) a selected sample of surgeons from the *Directory of the American Society for Plastic and Reconstructive Surgery*; (2) dentists randomly selected from the *Directory of the American Dental Association*; and (3) speech pathologists randomly selected from the *Directory of the American Speech and Hearing Association.* A total of 150 individuals from these groups responded (Table 2). Data were not available about cleft palate team membership. The questionnaire was also completed by a total of 990 dental hygiene, nursing, speech pathology, medical, and dental students and by 116 parents of children with cleft lip and/or palate. Thirty of the 116 parents were members of cleft palate parent groups. The parents resided in California, Louisiana, New Jersey, Oklahoma, and Texas.

Results

INFORMATION ABOUT CLEFT PALATE. The highlights of the results of the responses to items 1–14 of the questionnaire are summarized in Tables 1 and 2.

Students and Parents—Table 1 contains the results of the students' and parents' responses. The table indicates the following:

1. Most dental hygiene, dental, and medical students and most parents did not know the incidence of cleft palate in the United States.

2. Very few of the dental and medical students knew that the incidence of cleft palate differs among races.

3. Except for nursing students, the majority of students and parents knew that the incidence of cleft palate differs between males and females.

4. Eighty-one percent of the dental hygiene students and 49 percent of the nursing students did not know that children with cleft palate have a higher incidence of hearing loss than noncleft children. The majority of the other students and parents knew that children with cleft palate have a higher incidence of hearing loss.

5. The majority of students and 45% of the parents believed that children with cleft lip and/or palate usually have psychological problems which account for a *cleft palate personality.*

6. Except for speech pathology students, approximately 40% of the students did not know that the ultimate goal of cleft palate treatment is to improve speech.

7. The majority of nursing students could not correctly define *cleft palate.* However, the majority of the other students and parents could do so.

8. Except for speech pathology students, the majority of the respondents could not correctly define the terms *submucous cleft palate* and *pharyngeal flap.* They also did not know the rationale for secondary surgical procedures.

9. Higher percentages of correct responses were obtained by parents who were members of cleft palate parent groups as compared to parents who were not members on the first 13 items.

10. On Item #14, when asked to indicate which professionals should be included as members of the cleft palate team, parents and speech pathology students identified more professional members of the cleft palate team than did the dental hygiene and nursing students. Eighty-four percent of the nursing students omitted the plastic surgeon. Ninety-eight percent of the dental hygiene students and 94% of the nursing students omitted the otolaryngologist; this finding seems reasonably consistent because a large number of these students did not know that there is a higher incidence of hearing loss in cleft palate. The majority of students and parents omitted the prosthodontist. Sixty-five percent of the nursing students and 74% of the parents omitted the orthodontist. Although very few of the students believed that parents considered themselves as team members, 20% of the speech pathology students, 5% of the nursing students, 4% of the dental hygiene students, and 2% of the parents listed the parent as a member of the team. Data were not available on this item for dental and medical students.

Professionals—The percentage of correct responses by dentists, plastic surgeons, and speech pathologists to items 1–14 on the questionnaire are presented in Table 2. The table indicates the following:

1. The majority of professionals did not know

TABLE 1. Number and percentage of correct responses by students and parents to items 1–14 on the cleft palate questionnaire.

item description	*dental hygiene*		*nursing*		*speech pathology*		*dentistry*		*medicine*		*parents*	
	n = 146		*n = 148*		*n = 63*		*n = 432*		*n = 301*		*n = 116*	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Part A												
1. Time of onset of cleft palate	33	72	76	52	48	77	241	56	180	60	82	71
2. Incidence of cleft palate in USA	17	39	87	59	42	67	77	18	117	39	23	20
3. Racial incidence of cleft palate	36	80	96	65	43	69	86	20	45	15	67	58
Part B												
4. Occurrence of cleft lip with cleft palate	45	98	130	88	62	99	384	89	273	91	107	93
5. Sex difference in incidence of cleft palate	45	98	72	49	50	80	263	61	186	62	66	57
6. Incidence of hearing loss in cleft palate	8	19	75	51	54	86	259	60	198	66	90	78
7. Psychological problems and cleft palate personality	1	4	39	27	27	44	12	3	30	10	63	55
8. Ultimate aim of rehabilitation in cleft palate	25	55	87	59	51	81	224	52	165	55	84	73
9. Incidence of delayed language in cleft palate	36	80	124	84	54	86	393	91	237	79	90	78
Part C												
10. Definition of cleft palate	38	83	60	41	48	77	388	90	258	86	66	57
11. Definition of submucous cleft palate	5	11	11	8	39	62	207	48	135	45	30	26
12. Definition of pharyngeal flap	0	0	1	1	37	59	86	20	51	17	47	41
13. Reasons for secondary surgical procedures	11	24	51	35	38	61	112	26	114	38	34	30
14. Member of team												

TABLE 2. Number and percentage of correct responses by dentists, plastic surgeons, and speech pathologists to items 1–14 on the cleft palate questionnaire.

item description	*dentists n = 36*		*plastic surgeons n = 53*		*speech pathologists n = 61*	
	N	*%*	*N*	*%*	*N*	*%*
Part A						
1. Time of onset of cleft palate	30	86	49	94	54	90
2. Incidence of cleft palate in USA	12	36	22	42	17	28
3. Racial incidence of cleft palate	2	6	12	24	1	2
Part B						
4. Occurrence of cleft lip with cleft palate	36	100	53	100	59	98
5. Sex differences in incidence of cleft palate	19	53	43	83	54	90
6. Incidence of hearing loss in cleft palate	23	64	51	98	59	97
7. Psychological problems and cleft palate personality	3	11	22	43	28	46
8. Ultimate aim of rehabilitation in cleft palate	12	36	36	68	28	46
9. Incidence of delayed language in cleft palate	29	83	30	57	45	75
Part C						
10. Definition of cleft palate	33	92	51	98	59	98
11. Definition of submucous cleft palate	17	49	48	91	50	82
12. Definition of pharyngeal flap	16	47	50	96	48	80
13. Reasons for secondary surgical procedures	19	53	49	94	42	70
14. Members of team						

certain epidemiological facts about cleft palate. Specifically, they did not know the incidence of cleft palate in the United States, nor the racial differences in the incidence of clefts. Sixty-four percent of the dentists, 58% of the plastic surgeons, and 72% of the speech pathologists could not correctly indicate the frequency of occurrence of cleft palate in the United States. More than 75% of the professionals did not know that there is variation in the incidence of clefts in different races.

2. The majority of professionals felt that children with cleft palate usually develop a *cleft palate personality.* Although frequently incorrect, plastic surgeons and speech pathologists did better on this item than dentists.

3. Only 32% of the plastic surgeons were unaware that the ultimate goal of management is to improve speech; but the majority of dentists (64%) and speech pathologists (54%) were unaware of this.

4. When asked to indicate what professionals should be team members, 69% of the dentists omitted the otolaryngologist, although the majority of dentists knew that there is a higher incidence of hearing loss in cleft palate. The majority of the speech pathologists and 47% of the dentists omitted the prosthodontist. Very few of the dentists, plastic surgeons, and speech pathologists included the psychologist or psychiatrist as a member of the cleft palate team. This is surprising because the overwhelming majority of professionals felt that cleft palate children typically develop an abnormal personality. On the other hand, this is not surprising because many cleft palate teams do not have psychologists and/or psychiatrists.

5. Plastic surgeons obtained higher percentages of correct responses on 9 of the 14 items. The average percentage of correct responses, from highest to lowest, was as follows: plastic surgeons, speech pathologists, and dentists.

EXPERIENCE WITH CLEFT PALATE. The results of responses to items concerning experience and training are presented in Tables 3, 4, and 5.

Students and Parents—Tables 3 and 4 contain the results of the students' and parents' responses to items 15 through 20 on the questionnaire. The highlights of the findings can be summarized as follows:

1. The majority of students had seen a patient with a cleft of the palate; however, more than one-third of the speech pathology and medical students had not. Although the nursing and speech pathology students had had more clinical

experience than the other students, the overwhelming majority of all students had had no clinical experience with cleft palate patients. For example 94% of the dental students and 90% of dental hygiene students had never had any clinical experience with cleft palate patients.

2. Approximately one-half of all the students had known someone with a cleft palate. Very few of the students had a family member with cleft palate.

3. Almost all of the dental hygiene, speech pathology, and dental students had the topic of cleft palate included in their coursework. However, more than 30% of the nursing and medical students had not had the topic included in their courses. Thirty-two percent of the parents felt that cleft palate had not been adequately discussed with them.

4. The majority of nursing and medical students as well as parents had not done any reading about cleft palate. However, members of parents' groups had done more reading on cleft palate than parents who were not members of a parents' group.

Professionals—Table 5 contains the results of the professionals' responses to items concerning experience with cleft palate.

1. Although 96% of the plastic surgeons and 87% of the speech pathologists had worked with cleft palate patients, 56% of the dentists had not.

2. Almost all of the plastic surgeons and speech pathologists had had training in cleft

TABLE 3. Number and percentage of "yes" responses of the students to items 15–20 on the cleft palate questionnaire.

item description	*dental hygiene*		*nursing*		*speech pathology*		*dentistry*		*medicine*	
	n = 46		*n = 148*		*n = 63*		*n = 432*		*n = 301*	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Part D										
15. Have you ever seen a cleft of the palate?	31	68	116	79	40	64	311	72	195	65
16. Have you ever known an individual with a cleft palate?	24	53	71	48	32	52	233	54	156	52
17. Does any member of your family have a cleft palate?	1	4	7	5	4	7	8	2	3	1
18. Have you ever worked with a cleft palate patient in your clinical experience?	4	10	38	26	14	23	25	6	48	16
19. Has the topic of cleft palate ever been covered in your coursework?	46	100	88	60	59	95	371	86	207	69
20. Have you ever done any reading on the topic of cleft palate?	31	68	66	45	54	86	241	56	96	32

TABLE 4. Percentage of "yes" responses of the parents to items 15–20 on the cleft palate questionnaire.

item description	*parents*					
	member of parent group		*non-member*		*total*	
	n = 30		*n = 86*		*n = 116*	
	N	*%*	*N*	*%*	*N*	*%*
Part D						
15. Have you seen any other cleft of the palate?	27	93	68	80	99	86
16. Have you known anyone else with a cleft palate?	25	86	67	78	95	82
17. Does any other member of your family have a cleft palate?	9	31	14	17	27	24
18. Have you helped anyone else with a cleft palate?	8	28	16	19	26	23
19. Has the topic of cleft palate ever been discussed with you?	19	64	62	73	78	68
20. Have you done any reading on the topic of cleft palate?	14	47	18	21	39	34

TABLE 5. Percentage of "yes" responses of the dentists, plastic surgeons, and speech pathologists to items on the questionnaire concerning exposure to cleft palate.

item description	*dentists* $n = 36$		*plastic surgeons* $n = 53$		*speech pathologists* $n = 61$	
	N	%	*N*	%	*N*	%
Have you ever worked professionally with cleft palate individuals?	15	44	50	96	53	87
Was the topic of cleft palate included in your professional training?	27	75	51	98	61	100
Have you done any reading on cleft palate?	24	67	53	100	56	93

palate and had done reading on the topic. However, 25% of the dentists had never had any training in working with cleft palate patients, and 33% had never done any reading on the subject.

3. Plastic surgeons and speech pathologists had had more experience and training in cleft palate than dentists. This is not surprising in view of the finding that plastic surgeons and speech pathologists knew more basic information about cleft palate.

COMPARISON BETWEEN STUDENTS, PARENTS, AND PROFESSIONALS. As would be expected, professionals typically knew more about cleft palate and had had more experience and training than parents or students. The ranking of respondents on the basis of the percentage of correct responses, from highest to lowest, and the ranking of the respondents on the amount of exposure to cleft palate suggests, as would be expected, that there is a relationship between knowledge about cleft palate and experience. For example, the plastic surgeons ranked first in both categories.

It is both interesting and reasonable to note that the parents frequently knew more about cleft palate and had had more experience with it than was true for students. The evidence did not show a consistent relationship between students' level of training and knowledge and experience with cleft palate.

Discussion

The majority of students and professionals and 45% of the parents believed that children with cleft palate typically develop a *cleft palate personality* marked by abnormal psychological adjustment. Several writers have suggested that there is no such thing as a *cleft palate personality* (Hackbush, 1951; Ruess, 1958; Schweckendiek and Danzer, 1970; Wirls, 1969; Wirls and Plotkin, 1971). In reviewing the literature about psychosocial aspects of cleft palate, Phipps (1965) pointed out that there is a " . . . marked discrepancy between clinical-logical opinion and research evidence on the frequency and severity of psychosocial problems of children with cleft palates." Many individuals who work with people who have clefts report a myriad of psycho-social problems. However, most of the studies using standardized tests measuring adjustment or personality deviations fail to show any differences. McWilliams and Smith (1973, p. 51) feel that " . . . it is just possible that society may create pressures which it then minimizes and denies so that the person with a cleft, or handicapped people in general, experience the subtle and not so subtle forms of discrimination which majorities practice against minorities."

It should be pointed out that all professionals should not be expected to be experts. For example, it is undoubtedly better for many general dentists to refer a child with a cleft lip and palate to a specialist who treats many such patients. Likewise if a speech pathologist sees a child with a cleft only once in every four or five years, then referral may simply be an acknowledgment of the fact that some professionals have specialities and that they may be better equipped to manage individuals with cleft palates. Thus, it is essential for professionals to know how to make referrals to appropriately trained professionals who continue education in their specific sub-specialities.

Conclusions

It can be concluded from these results that: (1) parent groups appear to have served a useful purpose in providing parents with information about cleft palate; (2) with increased academic training and clinical experiences with cleft palate, students and profes-

sionals have more information, and (3) programs of professional education about cleft palate are essential.

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Appendix

Key to the Questionnaire

Part A: Multiple Choice

1. The factors responsible for the occurrence of cleft palate become operative during:
   a. the first trimester of pregnancy
   b. the second trimester of pregnancy
   c. the third trimester of pregnancy
   d. the neonatal period
2. The frequency of occurrence of cleft palate is highest among:
   a. Caucasians
   b. Blacks
   c. Orientals
   d. the frequency is the same for all races
3. In the United States, cleft palate occurs in:
   a. 0.1
   b. 0.9
   c. 1.8
   d. 2.5-per 1,000 births.

Part B: True-False

F 1. A cleft of the palate always includes a cleft of the lip.
T 2. The incidence of occurrence of cleft palate differs for males and females.
T 3. Children with cleft palate have a higher incidence of hearing loss than the non-cleft population.
F 4. Due to the stress and adverse conditions that children with cleft palate undergo in life, especially in the early years of life, the majority of them develop certain psychological defense mechanisms which account for the "cleft palate personality."
T 5. The ultimate aim of the rehabilitative treatment of the cleft palate patient is improvement in the patient's speech.
T 6. The incidence of delayed language in cleft palate children is higher than in non-cleft children.

Part C:

1. What is a cleft palate? *Congenital fissure in the median line of the palate which may extend through the uvula, soft palate, and hard palate.*
2. What is a submucous cleft palate? *Condition in which the surface tissues of the hard or soft palate unite but the underlying bone or muscle tissues do not.*
3. What is a pharyngeal flap? *Surgical procedure to aid in achieving velopharyngeal closure; consists of transplanting a flap of mucous membrane and muscle from the posterior pharyngeal wall into the soft palate.*
4. Why would secondary surgical procedures be used in children with cleft palate? *Improve speech.*
5. The team approach is frequently used in the rehabilitative treatment of individuals with cleft palate. List those professionals who should be part of this team:
   a. surgeon
   b. dentist
   c. speech pathologist
   d. pediatrician
   e. otolaryngologist
   f. social worker
   g. psychologist, psychiatrist
   h. nurse
   i. audiologist, geneticist, radiologist, orthodontist, pedodontist, prosthodontist (others)

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