The purpose of this survey was to determine the general public's awareness and knowledge of cleft palate. Telephone questionnaires were completed by a random sample of 1,200 persons, 200 in each of six cities within four states. The results indicated only limited information and awareness of cleft palate. Suggestions for improving general public awareness and educational programs are discussed.

Ortiz-Monasterio (1975) indicated a need for public education about cleft palate. He stated: "Educating the public is quite important. Defects 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" (p. 186).

The American Cleft Palate Association's (ACPA) involvement in public education is approximately 20 years old. In 1966, a committee was charged with investigating the "total area" of parental relations in cleft palate management, and in 1968, an ad hoc committee was appointed to develop educational materials (Wells, 1979). Knowing that there was a need for public education and that those interested in cleft palate might not be able to attend annual meetings, ACPA established the American Cleft Palate Educational Foundation (ACPEF) in 1973. The Foundation publishes educational materials and provides information to the public, parents, and patients. The March of Dimes Birth Defects Foundation¹ and the National Society for Crippled Children and Adults² also publish and distribute public education materials. In addition, an organization for parents and patients, the National Cleft Palate Association (NCPA)³, was established in 1984. This Association emphasizes public and professional education.

Although information is available about parents' and professionals' awareness and knowledge of cleft palate (Crocker and Crocker, 1970; Finnegan, 1982; Hill, 1955; Lass et al, 1973; Pannbacker, 1977; Pannbacker et al, 1979; Schuerle et al, 1984; Spriestersbach, 1961, 1966, 1973; Tretsven, 1965; Van Demark and Van Demark, 1970; Walesky-Rainbow and Morris, 1978), no such information currently exists in the literature about the general public. The purpose of this survey was to determine the general public's awareness and knowledge of cleft palate.

**METHOD**

The authors constructed a questionnaire concerned with respondents' knowledge about cleft palate, including its definition or description, etiology, treatment, and associated problems, as well as exposure to individuals with cleft palate and to literature about cleft palate. The question-
naire also contained items about the respondents’ demographic characteristics, including education and occupation.

All questionnaires were administered by means of telephone calls made on a random basis. The random selection procedures consisted of two computer-generated lists of random numbers. One list was used for the selection of the page in the city’s telephone directory, and the other list was used for the selection of the entry on that page in the telephone directory. Only private residences were used, i.e., no business offices.

The format for the telephone interview was as follows:

"Hello. My name is... and I am working as a research assistant for.... We are conducting a telephone survey by simply randomly selecting telephone numbers from the directory and I would like to ask you to participate in this survey by answering a few simple questions about the disorder of cleft palate. It should take no more than a few minutes to answer these questions. I can assure you that the name of anyone who participates in this survey will not be revealed. OK? If you do not know the answer to any question, please do not hesitate to say you don’t know. In addition, you may choose not to answer some of the questions."

The questionnaire was completed by a total of 1,200 respondents, 200 in each of six cities (Morgantown, W. VA; Shreveport, LA; El Paso, TX; Fort Worth, TX; San Antonio, TX; and Pittsburgh, PA).

RESULTS

The majority of the respondents (50.9%) had no more than high school education. Occupations were classified using Hollingshead’s (1975) nine-point scale. Twenty-four percent of the occupations fell into categories one through three, which includes service workers, unskilled workers, semi-skilled workers, and machine workers. Sixty-one percent of the occupations fell into categories four through seven, which includes small business owners, skilled workers, clerical and sales personnel, technicians, semi-professionals, and farm owners. The remaining 15 percent fell into categories eight and nine, which includes administrators, proprietors of medium and large businesses, and major professionals. The distribution of occupations in this sample is consistent with the percentages reported in the 1970 United States Census (U.S. Bureau of the Census, 1973), and thus, this sample was not biased in terms of socioeconomic status.

The percentage of “yes” and “no” responses are presented in Table 1. A detailed analysis of the respondents’ answers will be sent to any reader who requests it. The following is a summary of the major findings of the survey:

1. More than half (54.8%) of the respondents had never heard of cleft palate.
2. Of the 543 respondents who had heard of cleft palate, 18.4 percent could not define or describe cleft palate. Moreover, of those who said they could define or describe cleft palate, approximately 45 percent provided incorrect definitions or descriptions.
3. A total of 50.6 percent of the respondents indicated that they knew what caused cleft palate. The majority (84.7%) of these respondents indicated that cleft palate was a birth defect or genetic problem.
4. More than half of the respondents (52.7%) indicated that persons with cleft palate have speech problems, while cosmetic, dental, and hearing problems accounted for only 6.3 percent of all the problems noted.
5. The majority of respondents (81.9%) believed that cleft palate can be corrected. Almost all respondents mentioned surgical intervention, while only 3.5 percent included prosthetic management.
6. Almost 91 percent of the respondents indicated either that cleft palate could not be prevented or “do not know”.
7. While 38.7 percent of the respondents knew that a cleft palate does not always include a cleft of the lip as well, more than half (61.3%) either thought that it did (14.4%) or did not know (46.9%).
8. Very few of the respondents mentioned professionals other than the speech pathologist (17.8%) or plastic surgeon (14.6%) as professionals who provide treatment for cleft palate. For example, only 0.7 percent included the prosthodontist.
9. If they or a relative or friend had a cleft palate, 70.5 percent of the respondents would recommend treatment from a physician (23.0%), a hospital (18.5%), a family doctor (9.2%), a plastic surgeon (7.6%), a speech pathologist (5.1%), an oral surgeon (41.8%), or a cleft palate team (3.3%).
TABLE 1 A Summary of Responses to Selected Interview Items*

<table>
<thead>
<tr>
<th>Item</th>
<th>% Yes</th>
<th>% No</th>
<th>% Do Not Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition or description of cleft palate</td>
<td>81.6</td>
<td>18.4</td>
<td>---</td>
</tr>
<tr>
<td>Causes of cleft palate</td>
<td>50.6</td>
<td>49.4</td>
<td>---</td>
</tr>
<tr>
<td>Treatment of cleft palate</td>
<td>81.9</td>
<td>2.8</td>
<td>15.3</td>
</tr>
<tr>
<td>Prevention of cleft palate</td>
<td>9.6</td>
<td>29.3</td>
<td>61.1</td>
</tr>
<tr>
<td>Occurrence of cleft palate only</td>
<td>14.4</td>
<td>38.7</td>
<td>46.9</td>
</tr>
<tr>
<td>Known someone with cleft palate</td>
<td>34.5</td>
<td>60.2</td>
<td>5.3</td>
</tr>
<tr>
<td>National professional organization</td>
<td>26.3</td>
<td>12.9</td>
<td>60.8</td>
</tr>
<tr>
<td>Interested in learning more about cleft palate</td>
<td>57.3</td>
<td>42.0</td>
<td>0.7</td>
</tr>
</tbody>
</table>

*N = 543

However, 7.1 percent indicated that they did not know where they would seek treatment.

10. The majority of respondents (64.5%) indicated that they had not known anyone with a cleft palate. Of the respondents who had known someone with a cleft palate (34.6%), 72.6 percent of these reported that they had friends or acquaintances with cleft palate.

11. The most frequently mentioned problem of these friends or acquaintances known to have a cleft palate was speech (51.2%). Almost two-thirds (62.6%) of these persons had received treatment from professionals and of these, more than half (56.4%) were satisfied with the treatment that they received.

12. More than half of the respondents (60.2%) had no opinion about the overall quality of treatment for persons with cleft palate. A total of 11.6 percent said “poor” (2.4%) or “average” (2.4%) or “excellent” (6.8%).

13. More than one-fourth (26.3%) of all respondents believed there was a national organization that represents the professionals who provide treatment for cleft palate. However, when asked to name the organization, only one identified the American Cleft Palate Association. In fact, 91.6 percent of the respondents answered “do not know” to this question.

14. More than half of the respondents (57.3%) were interested in learning more about cleft palate. There was a preference for television programs (20.6%) or printed information (70.5%) as opposed to educational formats such as radio programs (7.8%) or workshops (0.1%).

15. A total of 49.4 percent of all respondents had never read anything about cleft palate nor heard it discussed. Moreover, of those respondents who had read or heard about cleft palate, 38.6 percent had read magazines or books, and 39.1 percent had heard it discussed in a class, a conversation, or on a television program.

SUMMARY AND IMPLICATIONS

The findings of the present survey indicate that, as was also the case for students, parents, and professionals (Finnegan, 1982; Lass et al, 1973; Pannbacker et al, 1979), the general public had less than adequate information and awareness of cleft palate. Information was especially lacking about cleft palate teams. Very few respondents (2.3%) would seek or recommend treatment from a cleft palate team, despite the fact that there are cleft palate teams or centers located in five of the six cities surveyed (Morgantown, El Paso, Fort Worth, Pittsburgh, and San Antonio) (ACPA, 1984). The advantage of an interdisciplinary team approach to the management of cleft palate has been supported by several writers (Bleiberg and Leubling, 1971; Kennedy et al, 1973; Koepp-Baker, 1963, 1979; Krogman, 1979; McWilliams et al, 1984; Morris et al, 1978; Rampp et al, 1984; Spriestersbach, 1968).

It was also interesting that most respondents did not know there was a national organization that represents the professionals who provide treatment for cleft palate. Furthermore, only one of the 1,200 respondents mentioned the American Cleft Palate Association.

These findings indicate a strong need for increased public information and awareness programs. The responsibility for providing educational information about cleft palate to the general public should involve national organizations such as American Cleft Palate Educational
Foundation and the National Cleft Palate Association. Another method of disseminating educational programs would be to involve cleft palate teams and parent-patient support groups in outreach programs to the general public. The data from this survey do provide guidelines to those developing programs of public information and education. Specifically, there appeared to be a preference for certain formats for such programs (e.g., television and printed information).

Specific activities to develop awareness and understanding of cleft palate could include:

1. A media blitz with feature articles in the local newspapers, and public service spot announcements on television, radio, or both
2. Theaters at public events to show informative films
3. A special week with activities and discussions directed by parents, patients, and professionals
4. Encouraging human interest stories written about or by parents or patients to learn about their experiences with cleft palate
5. A visit to a cleft palate center or parent-patient support group
6. Developing resource files of references and resources such as films
7. Encouraging cleft palate centers and parent-patient support groups to assemble materials into kits and collections
8. Developing lists of resource persons with expertise in cleft palate so that professional, service, and other organizations could easily locate speakers and resource persons
9. Attention-getting methods to disseminate information available in published form from local, state, and national agencies.
10. Disseminating information about cleft palate via printed materials with a personal follow-up of that material.

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