Changing Concepts in the Treatment of Craniofacial Anomalies

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In January, 1943 at the Speech Clinic of the Pennsylvania State College a course in the construction of speech appliances for children with cleft palates was held. The Department of Health organized this course under the Social Security Act, and it was designed to acquaint dentists and oral surgeons with the medical, dental, speech and psycho-social problems of the cleft palate patient. The direct outcome of this conference was the formation of the American Academy of Cleft Palate Prosthesis. Initially the membership numbered thirty-three.

In 1951 the name of the organization was changed to The American Association for Cleft Palate Rehabilitation. It now opened its membership to persons possessing any of the following degrees: Doctor of Dental Surgery, Doctor of Dental Medicine, Doctor of Medicine, Doctor of Philosophy, Doctor of Education, and to persons possessing a certificate of professional competence in their fields. The objectives of the reorganized group were: to stimulate specialistic and public interest in, and more exact knowledge and improved practice of, the science and art of the rehabilitation of persons with a cleft palate and associated deformities of the mouth and face. The membership numbered 164.

During these formative years it is noted that the interest centers around the Model; i.e., the cleft palate patient. The “players” mentioned previously fall into line as their interests and involvement increases. It became obvious that the diagnosis, investigation and treatment plan of these patients should not be one of surgery only or prosthesis only, but consist of a group of specialists working as a unit. The organization throughout this country of coordinated groups of specialists in what became known as the Cleft Palate Team emerged as an approach to study and rehabilitation of the cleft lip and cleft palate patient. The number of multidisciplinary teams increased from one in 1949 to 46 in 1955. (Recently published directories in the U.S. list 138 teams staffed by approximately 2,500 professionals.) Medical and dental personnel were responsible for establishing most of the teams: the average team began with 9 members and

Presidential Address given at the Thirtieth Annual Meeting, American Cleft Palate Association, Phoenix, Arizona, April 15, 1972.

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increased to 14, the biggest increase involved speech and hearing personnel. Because of this increased interest and addition of new members, the *American Cleft Palate Association* came into being in 1961. It was reasoned that the Association would reflect both the interdisciplinary interests (medicine, surgery, speech pathology, orthodontia, prosthetics, audiology, psychology, etc.) and the other activities of research, clinical and administration. 530 members were now recognized.

For the past 10 years the interdisciplinary personnel of most centers has remained relatively unaltered (too few additions of geneticists, cardiologists, pediatricians, dermatologists, ophthalmologists, and neurosurgeons, I might say) but what has been quite obvious is that the *Model* has changed. Yes, we are still seeing as many cleft lip and palate cases, but marked increase in craniofacial anomalies is being observed everywhere. It is conceivable that other malformations found in association with clefts may not become apparent until additional disciplines and methods are involved. For example, at our Clinic at the University of Illinois, we found an increased incidence of congenital heart defects in children with facial clefts, particularly in girls with cleft palates alone. Furthermore in a postmortem study of 32 children with cleft lips or palates 21 or 62.5% were found to have severe congenital cardiac malfunctions.

Permit me a moment to digress from our review of history to help me fortify these statements.

Congenital malformations represent an increasingly important part in the total load of human disease. It is true that this body of diseases has come to represent a main challenge to medicine now that infections and nutritional diseases are better understood and controlled. Approximately 7 percent of human term newborns suffer from some aberration of development which will necessitate substantial and prolonged medical attention and/or shorten their expected life span. The actual human malformation rate is indeed much greater than this, for the incidence of developmental anomalies in abortuses and stillbirths is remarkably high. Of particular interest to this group is that orofacial clefts constitute approximately 13 percent of all reported anomalies and represent the second most common malformation. The tremendous psychological burden and long-term medical care and cost to parents and other contributory agencies as well as the affected individual are incalculable.

From both clinical observations and animal experimentation we now know genetic factors play a significant role in the etiology of certain congenital malformations; i.e., in extodermal dysplasia, cleft lips and central nervous system lesions. The importance of hereditary factors is quite clear. Recently a whole spectrum of human developmental malformations have been shown to be due to minor changes in the chromosome complements of individuals and linked directly to cases of mongolism, Turner’s and Klinefelter’s Syndrome, and others.

At the other end of the spectrum are those malformations which are due
to pure accidents of sudden environmental change during critical stages of embryogenesis. Rubella infection, thalidomide and x-ray radiation are classical examples of environmental factors causally related to human congenital anomalies.

The National Foundation—March of Dimes now concentrates all of its energies and money to the research and study of birth defects, not a small number of which are orofacial deformities.

At its annual meeting of 1971 the American Cleft Palate Association proposed "that the Association go on record as favoring a change of name and purpose of the Association so that it will encompass craniofacial anomalies." That proposal (partially unfilled) and the prospective consequences represent the most important news in this field, and as I have stated a change in our "Model." To most of us, however, this has been a gradual progression of interests over a period of many years. It should be recognized that congenital malformations, morphologic and metabolic, are being studied with increasing interest by an ever-increasing array of disciplines whose interests range from molecular and cell biology to population genetics and epidemiology. This concentration of interests represents more than the current fashion in science. It stems from a minimal recognition of the relatedness of such problems to the public health and the fundamental import to basic science of the knowledge that can be gained from these studies.

Craniofacial anomaly is certainly not a new interest to the American Cleft Palate Association. Our association was directly involved in the International Symposium on Congenital Anomalies of the Face and Associated Structures in 1959 at Gatlinburg, Tennessee, and some of you in the audience were there and participated. It brought together for one of the first times geneticists, embryologists, anatomists, virologists, in addition to clinicians interested in congenital anomalies. In 1960 the first conference on congenital malformations was sponsored by the National Health Foundation. In 1965, a symposium on oro-facial anomalies in Wilmington, Delaware, found a number of you on the program. Another conference on craniofacial deformities sponsored by Longacre and Warkaney followed in Cincinnati. In 1969 the combined faculties of the Universities of Miami, Minnesota and Illinois gave a symposium on Cleft Palate and other craniofacial anomalies. Attendance and interest were outstanding in all these conferences. Another International Conference was held at New York University Medical Center on Craniofacial Anomalies under the direction of Drs. Converse and Pruzan-sky this past fall. Many national and foreign dignitaries participated, and it was thrilling to see such outstanding persons present their material.

You can see that over the past decade there has been increasing concern for congenital malformations aside from those of pure cleft lip and cleft palate. Even the thalidomide tragedy made us terribly conscious of environmental factors and their effects on the ecology of the fetus. The profile
of pediatric practice has been changing. Warkaney reports that among the advantaged nations ten times as many children die as a result of congenital malformation as of five contagious diseases once greatly feared. This is a relative change characterized on one hand by the reduced morbidity due to infection, and on the other by increased recognition of a great variety of congenital morphologic and metabolic anomalies.

The emphasis is definitely moving toward the direction of including other malformations so that the same interests, energies and research once expended toward the correction of cleft lip and palate are now being used to support the study and correction of craniofacial anomalies. This in no way should dilute the study of cleft lips and/or cleft palates but truly form a bridge of communication between scientists in biology, medicine, dentistry, speech pathology and allied fields interested in craniofacial birth defects.

I have brought you up to date from where we were to where we are—now, whither does't we go? What then is the future of the American Cleft Palate Association. If the Association's interests are to broaden then who should be included? Who should be excluded? Should any limitation be set for future growth of the Association? Are the ethics of all professional groups the same?

Some members see the changing and expanding interests as a threat to their own special lines of endeavor. Others in the large University atmosphere see their patient caseload and indeed their research interests broadening to include genetics, teratology and craniofacial biology. Coming from the staff of a center exhibiting the latter interests I cannot help but inject that I do not think there is a single member of our Association who is not already taking care of a wide variety of craniofacial anomalies in addition to clefts of the lip and palate.

The various segments of our professions have traditionally organized themselves to attain professional identity and to promote the advancement of knowledge and skills which have permitted the development of scientific medical practice that could hardly have been imagined 50 years ago. In the process however, each segment has attained a degree of autonomy that encourages a disinterest, at times, amounting to disdain, for what the other segments are doing. This is obvious where separate specialties have considerable difficulty in projecting their sights beyond their self-determined objectives. At every level of professional activity, a lack of cohesiveness and a reluctance to appreciate even the need for combined efforts to attain objectives is seen.

I would think that this Association has proven over the past 20 years that a continuous "ESPRIT DE CORPS" has evolved from our daily multidisciplinary actions and has eliminated much of what has just been said. Each specialist in his own field possesses a thorough, sound and trained acquaintance with the fields of his co-workers. We are all in the habit of working together on problems that are refractory to attack by a
single discipline. Yet, deep concern abounds regarding our future. The pleasantries portrayed at this meeting and at others in the past would lead the uninitiated to believe that this is a smooth running potential virile society where steady membership growth will continue ad infinitum. I have a much brighter outlook today after the splendid way both Council and the members present at this annual business meeting thoughtfully reasoned the future of our Association. Having sat on Council for approximately 6 years to include those as vice president and president it has been exceedingly difficult to juggle and at times make sense out of the present 3 disciplined methods of representation on Council, official offices in the Association and various committee assignments. It definitely has led at times to ineffective individuals in slots that for all intents and purpose has not been to the benefit of our Association. I must be the first to admit to the excellence of this program arranged by Gene Powers and his Committee. However, what about a less fortunate President and membership who must according to tradition have a program chairman selected from an elected office on the present rotation system. Would it not be more rational that the Program Chairman be selected by direct appointment by the President-elect thereby affording a more logical judgment of leadership from the Presidential office.

The results of the polling of the membership in response to my letter to you all does to some extent indicate the trend for the future. Many of you sent me letters indicating your confidence that as the interests and name of our organization had changed in the past it not only survived but grew and developed maturity in its new field of endeavor. The members here in formal sessions yesterday have definitely given their approval toward broader interests which must be invited or else we are doomed to stagnation. The proposed by-laws change to add a student membership, denotes foresite by all of you toward recruitment of a sharp new generation of scientists. Your Council has initiated the proposal of an establishment of an Education Foundation for further study of our yet unsolved problems by this younger generation.

On Tuesday evening I landed here in Phoenix in the midst of a sand-storm in anticipation of this Meeting. I wondered whether the sand was some sort of omen. I am pleased to see before me a compact and yet well-diversified Association who has not decided to keep its head buried in an Arizona type sand but who like the proud peacock has aired its feathers and now plans to spread its interests to include and involve other scientists from allied fields for the betterment of the Association and indeed all mankind.