Pediatric Facial Plastic and Reconstructive Surgery

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Chapter 9: Organization of Cleft Teams

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There are many controversies in the care of cleft patients today. In spite of this, general agreement would be most likely on the statement that cleft care in the 1990s is best delivered with a coordinated, organized team effort. Victor Veau is credited with originating the cleft palate rehabilitation team. An ideal cleft team was defined by Whitehouse as "A close, cooperative, democratic, multiprofessional union devoted to a common purpose - the best treatment for the fundamental needs of the individual". This team concept allows the individual members of the team to fully utilize their particular mix of talents and training while at the same time providing a unified and comprehensive plan of care for the patients.

Table 1. *Specialities represented within a cleft team*

- Team concepts
- Personnel
  - Specialities involved
    - Plastic surgery
    - Otolaryngology
    - Oral Surgery
    - Orthodontics
    - Speech pathology
    - Genetics
    - Pedodontics
    - Child psychiatry
    - Pediatrics
    - Nursing
    - If craniofacial patients are evaluated, the group should also include ophthalmology and a neurosurgeon
    - Social work
  - Support personnel
    - Coordinator
    - Scheduling assistant
- Patient evaluation
  - Individual evaluation versus team visits
  - Coordination of surgery
  - "Staffing"
  - Handouts
- Treatmet
  - "In house" versus coordination of local specialties
- Follow-up/outreach.

The pooling of patients from what would otherwise be several individual practices into a central cleft team also allows all members of the team to continue their education process and improve the care of each individual patient that comes to see them. This arrangement allows the team to become "patient centered" rather than "speciality centered", a concept first advocated by Koepp-Baker. This interaction between various specialties and subspecialty groups further provides an optimal training both in treatment techniques and interpersonal relationships for young surgeons and residents. In this setting they are exposed to a number of different viewpoints and protocols, which allows them to begin the filtering and molding process that is necessary as they develop their own concepts of cleft care. It is hoped that this educational process will foster the belief that the care of cleft patients must transcend egotistical and financial concerns of the indivudal team members. The purpose of this chapter is to generally outline a team system of cleft care with specific references to the care given by the cleft team at the University of Iowa.

Obviously, it is impossible to expect that one cleft team will be an exact copy of another. Based on an individual team's strengths and weaknesses, it will develop its own particular characteristics. Regardless of these variations, the premise of this chapter is that the team concept of care is an example of the whole being greater than the sum of its individual parts, thus allowing each group to best serve patients.

Personnel

Involved Specialties

Surgical

Ideally, the specialties represented within a cleft team would include those listed in Table 1, namely plastic surgery, otolaryngology, oral surgery, orthodontics, speech pathology, genetics, pedodontics, prosthetics, child psychiatry, pediatrics, nursing, and social work. At a minimum, surgical, nursing, dental, speech, and social work problems must be addressed and adequately covered. As stated previously, the surgical endeavors of many of these groups may overlap in part, but rather than being a liability within the cleft group, this can be used as a distinct advantage. First, regarding training, it allows residents from different services to have exposure to problems that are being both diagnosed and treated from different perspectives. This optimally provides for a free and open exchange of ideas between specialties and gives the trainees experience in different methods of handling complications. Another decided advantage of having several groups of people performing the same operation is increased convenience for the patient. No longer is the patient required to wait until an opening arises in a given surgeon's operating schedule. With multiple surgeons performing a given procedure, the patients can be scheduled at times that are more convenient for them and the cleft team no longer has to be idle during times of national conventions or individual vacations.

The credentialing of surgeons to perform given procedures has been and will remain a difficult problem. Prior to assuming a position as a staff member of the cleft team, an individual should have completed sufficient training that he or she is comfortable not only with the surgery itself, but also with the handling of complications. Preliminary training under a variety of teachers on a heterogeneous patient population is ideal, as this allows the

individual to develop his own approach using the best of his exposure from each source. This prevents overdependence on a narrow viewpoint of technique or philosophy, thus providing the training surgeon with an adequate variety of surgical options to allow any surgical problem encountered to be successfully overcome.

Everyone involved with the care of clefts realizes that the most critical measurement of success is long-term outcome. Thus, although no training program can provide the life-long follow-up necessary for true judgment of results, a good training program should provide adequate postoperative follow-up of at least 2 years so that some intelligent judgment can be made regarding the outcome of the techniques applied. This follow-up and observation of results over time, both good and bad, is perhaps the most critical aspect of any given surgical education.

Dental

Dental development and hygiene, particularly in the very early stages of tooth eruption and deciduous dentition, need qualified care and future planning. An early regimen of proper oral hygiene is essential to future surgical orthodontic and surgical endeavors. Obviously, expert dental intervention is necessary beginning as early as birth in some cases with application of orthopaedic positioning devices, and continues until final, permanent, stable occlusion is established and maintained. The orthodontist and surgeon must work in symbiosis as neither can achieve an optimal result alone. Often because of long distances and frequent visits that are necessary during active orthodontic care patients and families will elect to have some of their orthodontic care done locally. This is certainly acceptable as long as there is communication between the local orthodontist and the surgeon and orthodontist in the cleft team. Specifics of dental care are beyond the scope of this chapter and will be described by other authors.

Speech

Speech problems in the cleft patient are well documented and continue to be a source of difficulty in some patient's everyday interactions. Early evaluation, therapy, and careful follow-up by speech pathologists experienced in working with cleft patients is essential. Increasing use of fiberoptioc evaluation requires close cooperation and interaction between the surgeon and speech pathologist. Speech pathologists play an extremely important role both pre- and postoperatively in surgical correction of speech problems. Indication for surgical intervention for the correction of cleft speech problems will be discussed by other authors.

Nursing

The nursing service provides an essential and often underappreciated role in the care of the cleft patients. A nurse who works consistently with the patients in clinic can provide tips on feeding and general day-to-day care that often may be overlooked by the medical staff. In reality these problems may be the most major frustrations the parents have in dealing with their new offspring. This same specialist should see the people in the cleft clinic, make rounds with the attending surgeons while the patient is in the hospital, and be available to take phone calls from the parents and coordinate the responses back to them. Again, along with the clinic coordinator, the cleft nurse should become a patient advocate and it is not unusual for a deep,

long-term bond to develop between the cleft nurse and the patient and their families. It is extremely important that cleft nurse specialists view their job as a stable, long-term commitment, and feel that they have the freedom to discuss any situation at any time with any team member.

Other Members of the Team

Other members of the team are often able to provide as much information and reassurance to the families during the initial visit and later as can those specialists already discussed. Specifically, genetics counseling is a vital and integral part of an initial cleft visit to any cleft team. Any guilt and accusations need to be dealt with, and factual information for further family planning must be given to the parents of the cleft child. Along with this genetics counseling, a general pediatric examination should likewise be carried out, the extent of which would depend upon the initial history and physical examination. Obviously, many children with clefts have additional special physical and psychological problems, and they will need to have these addressed every bit as expediently as their surgically correctable problems.

Although traditionally much emphasis is given to the medical and surgical members of the cleft team, anyone with experience in directing a large, integrated team caring for cleft patients realizes the truly indispensable contribution of a clinic coordinator, and reliable scheduling assistant. Every cleft team needs to have a dedicated full-time coordinator who ensures smooth patient flow during clinic days and maintains an ongoing line of communication between the patients' families and the necessary specialists on the team. This person, of necessity, will become a patient advocate and often will provide profound insights into family dynamics and a patient's state ofmind that are essential to a good outcome but would be otherwise impossible to elucidate. The wise surgeon will make good use of this information, giving it the consideration it deserves.

Because of the large number of surgeries scheduled and different surgeons involved, a centralized mechanism of scheduling must be implemented with a scheduling data base accessible by all members of the team. This prevents double bookings and individual unavailability, so that combined procedures can be smoothly scheduled and performed. Also, since nonsurgical members also have access to this schedule, optimal preoperative preparation and postoperative therapies can be performed.

Because of the magnitude of the anticipated procedures and related expenses, all families with newborn cleft children should have an initial visit with the social worker. At this point it is appropriate to identify potential family and financial problems that may surface under the stresses of the upcoming cleft care. Ideally this visit should occur at the initial visit to the cleft team and be followed up as deemed appropriate on an individual basis.

An important consideration is that as the completeness of the cleft team grows, so does the complexity and potential confusion for the cleft patients. It is not uncommon at the University of Iowa for a patient to have a scheduled return visit to our cleft clinic a month after the initial visit so that questions that have arisen since the initial visit can be answered. It is perfectly understandable that many parents are completely overwhelmed at the prospect of caring for a cleft child and are equally overwhelmed by the prospects of having to deal with so many new specialists who are attending to the care of their child. It is in this area that

the services of the clinic coordinator, the cleft nurse, and the scheduling secretary become most urgently needed.

Patient Evaluation

An idealized example of care for a patient with unilateral cleft lip and palate is presented. Visits to the clinic include both visits to individual specialists as well as team visits where multiple disciplines are seen. As much as possible, efforts are made to coordinate visits so that even if the entire team is not going to evaluate the patient, a number of individual specialists can evaluate the patient on the day of the visit.

Having a close working relationship and open communication, members of the team provide benefits when it comes to coordinating various surgical endeavors. We feel strongly that a number of procedures can be safely combined and performed under one anesthetic setting. We routinely perform myringotomy and tube placement along with other soft tissue surgeries and coordinate other dental and dental rehabilitation procedures in concert with soft tissue work. As long as the total time of the procedure is kept under 3 to 4 hr, we have not seenan increase in morbidity or surgical complications with this approach.

During each patient evaluation any of the members of the team may request that the patient be brought before the entire cleft team for a staffing. Occasionally, because of the extra time involved, patients may be reluctant to remain, but we have found that this staffing is essential for maintaining good communication between the involved specialists. Also we have found that this provides the ideal opportunity for the members of the team involved with scheduling to become aware of exactly what is being planned for this patient and to know who will need to be involved so that appropriate adjustments in surgical schedules can be made.

Treatment

Individual aspects of techniques and treatment will be covered elsewhere in the text. However, every specialist who practices at a referral institution must be aware that often coordination of an individual patient's care with local specialists may be necessary. Increasing occurrence of two-career famnilies, skyrocketing transportation costs, and expanding areas of coverage dictate that certain patients will not practically be able to come to a central cleft clinic for every single aspect of their care. Many times there are well-trained, experienced professionals available locally who are more than willing to provide ongoing care and follow-up. It is our feeling that these people should be maximally utilized and good relations with them must be maintained. This concept helps support the belief that referral to the university setting can be a two-way street. Each individual on the cleft team should expect to spend a sizable portion of his/her office time on the phone to local specialists each week. This close communication with local referring professionals is essential not only for the good care of an individual patient, but for the ongoing viability of the cleft clinic itself.