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Team Easing Problems for Cleft-Palate Child.

It's not easy growing up with this handicap. But UTHSCD specialists pool talents to help youngsters and parents achieve normal life.

DALLAS--Myra Davis (not her real name) swallowed hard when her obstetrician broke the news that although fine in all other ways, the Davises' new baby girl had been born with cleft lip and palate. He wanted to prepare them before they saw the child.

After the initial shock, Myra later told a friend, it wasn't so bad.

"After all," Myra, 28 and having her "first," thought, "it's not as if doctors today can't do something about it. I knew there was was an operation..."

What Myra didn't realize--and what the obstetrician did not prepare the Davises for--was the multiple related health, psychological and educational problems that were to arise for little Jenny in the coming years of her childhood. They did not know that cleft lip, often cruelly called "harelip," is a defect often associated with a host of other medical, surgical and dental problems.

According to Dr. Peter Sherrod, assistant profesor of pediatrics at The University of Texas Health Science Center at Dallas and coordinator of the craniofacial clinic at Children's Medical Center, the child with cleft palate often needs specialized medical care, dental attention and help from experts in other areas, such as speech and hearing therapists. Physical conditions associated with cleft palate may include other facial structural problems which, while not necessarily making the child unattractive, may contribute to health problems, he said.

This child may be more prone to allergies and infections of the tonsils, adenoids and ears, which may lead to loss of hearing. He or she may have speech impairment and develop digestive or nutrition problems as a result of the inability to chew food properly due to a "bad bite." The child may have vision problems as well as dental problems, requiring braces or oral surgery. Also, unless the cosmetic problem is minimal, there may be psychological problems for the child to cope with.

There are other hardships, too.

Even when medical and dental care is readily available, the family may find themselves caught in a maze of specialists, each treating one particular health problem. But the specialist is unable to make referrals on related ills or even answer the parents' questions not pertaining directly to his or her field. If the family is poor, they may not even know where to go for the most help.

Growing up is never easy. And to a child with multiple aesthetic and physical handicaps and frequent illnesses, it's even harder. As with many other illnesses and diseases, families such as the Davises often find the problems of the child affect everyone in the home.

Parents can get easily discouraged with the extra care needed by a sick child, the mounting bills for medical and dental care and the added emotional burdens. The other children may resent what they interpret as special attentions given to youngsters like Jenny. Thus, the child's problems may become, as sociologists say, "a family problem" with resulting unhappiness for everyone. The resulting tensions may turn this home into a battleground with wars being waged on all sides.

Another "battleground" Jenny will have to face is school. Bad experiences with other children who point and laugh will probably affect her self-esteem. If she feels disfigured, she may become shy and retreative. If she is absent often, either from physical problems or from pretended illness due to her inability to cope, she may fall behind in her work and then feel "dumb." If she gets sick easily, her activities, including attending school and playing with other children, may be drastically curtailed and she may first feel lonely, then unlikeable. Soon she will be literally left behind and left alone.

Luckily for Jenny, her pediatrician was aware of the work of the craniofacial team, as well as the operations on children performed by Dr.Kenneth Salyer, professor of surgery, also at the health science center's Southwestern Medical School, and prime mover in the organization of the team. Dr. Salyer is a pioneer in craniofacial surgery--surgery involving the jaws, hard palate and soft palates, pharynx, skull, bones of the cranium, bony orbits, eyelids, tear-duct system, air pathways, sinuses and related areas.

Dr. Salyer has developed one of the few craniofacial teams working together to attack these complex problems. One of only five in the United States and Canada, this team helps patients through the potentially confusing maze of specialists.

The craniofacial team, under the leadership of Dr. Sherrod, a pediatrician, is made up of representatives from his speciality and others including plastic surgery, otolaryngology, ophthalmology, neurosurgery, speech pathology, psychology, social work, nursing, audiology, orthodontics, pedodontics, prosthodontics, radiology and genetics. Also immediately available for consultation to the team are a variety of other specialists affiliated with Children's and the health science center.

"The team sees children (and adults in other clinics) with congenital and/or acquired craniofacial defects resulting in malformations of the head, eyes, nose, ears, jaws and mouth," Dr. Sherrod related. "These defects are often accompanied by other major problems, such as speech and hearing disorders, difficulties in chewing and other various visual defects. And any one or a combination of these problems can be emotionally traumatic to both the patient and the family. One of the strengths of the team approach, the team coordinator stressed, is that "we are dedicated to treating all aspects of the problems associated with craniofacial disfigurement.

"Furthermore," he continued, "modern care of these complex medical, dental and psychosocial problems is best managed by such a team of specialists. While our team is working together cooperatively, we have but one common goal: to help these patients like Jenny achieve their maximum capabilities and become happy, fit and productive persons."

All the specialists are involved in diagnosing and evaluating each case to determine how their particular areas can help the patient in solving his or her special problems. Dr. Salyer emphasized that their input is invaluable in planning surgical procedures as well.

"As a team we also need to gather as much information about the patient and his or her physical deformity as possible. We also need to know as much as possible about the child's environment which has incalculable influence on physical problems and/or illneses," said Dr. Sherrod. Craniofacial centers using the team approach have been in existence in the U.S. and Canada for only six years. And even today Southwestern's clinic is one of only five.

The other four also are at large research centers--The University of Toronto Hospital for Sick Children, the University of Philadelphia, the University of Virginia and New York University Hospital.

The Dallas team began in 1968 when a number of physicians and health-related specialists interested in the many problems associated with cleft lip and palate patients began meeting on a monthly basis. As time went on many patients began to be referred to this group. Within a few years the specialists were holding diagnostic and evaluation clinics three times a month, as well as beginning to do multidisciplinary teaching and holding case reviews.

"By 1973 we were organized into a truly interdisciplinary team of specialists with the necessary expertise and knowledge to properly evaluate, diagnose, reconstruct and treat patients with major craniofacial anomalies, as well as the more common orofacial defects, such as cleft lip and palate," said Dr. Salyer.

Now, according to team director, Sherrod, the group is working with about 100 patients a year.

What will happen to Jenny when she arrives for her evaluation and diagnostic session?

After a short wait in the cheery reception area decorated with picture-book wall hangings and sculpture designed with children in mind, Jenny and her parents will meet the whole team. There will be plenty of time to talk with the parents about the problem and discuss the child's history. Then it's off to a dental chair in the examination room where a full-time team of specialists, as well as appropriate part-time members, will listen while they take turns looking at and testing Jenny. This room, too, is full of pictures and toys--and even the dental chair is a bright yellow. Most of the health personnel wear street clothes. They joke with Jenny and make a game out of the examination, so Jenny is not frightened by a room full of serious-looking people in white uniforms.

Still sitting back in the chair, Jenny is given a simple speech test and practices saying words at the coaching of a speech pathologist. Next she will be given a more comprehensive test with a tape recorder and the speech pathologist will check for any damage. X-rays are ordered for the same day. Audiograms and other tests may be made by the team's audiologist.

The team then assembles in a conference room to discuss Jenny's problems. Everyone is asked for comments and then for suggestions for a program of treatment and
follow-up.

Jenny and her parents now join the team. Team members ask any questions that may have come up and request the names and addresses of any physicians or dentists to contact and send records to. In some cases the outside specialists may include psychotherapists and special education teachers. The team makes recommendations for an ongoing program of treatment and surgery, if required.

A long-range approach to all Jenney's related problems will be discussed with the parents. If she needs special help, such as medical or dental work that can be done in her community, or special schooling, speech therapy, or mental health/mental retardation services, referrals will be made for the patient or her family. Genetic counseling will also be offered, said Dr. Sherrod, who is also assistant director of the Birth Defects Center. Dr. Mary Jo Harrod, genetic counselor at UT Southwestern, participates in the initial evaluation conference and meets with the parents at that time.

Appointments are made for surgeries to be done at Children's for the next check-ups if surgery is not indicated at this time. Now Jenny is a full-fledged patient to be seen by the team as long as necessary.

Not only are children like Jenny, whose problems are severe enough, referred here. But the craniofacial team also sees children with such extreme abnormalities of the cranium and the face that they almost appear 'monsters.' Some of these procedures combine the approaches and techniques from neurosurgery, as well as plastic surgery, Dr. Salyer said, and their application to the common problems of the face have made it possible to help many of these unfortunate children.

Father of these reconstructive surgeries of the cranial/orbital/facial skeleton is French surgeon Paul Tessier, who performed the first intracranial hypertelorism correction in Paris in 1969. The first intracranial procedure at Children's was done by M. Tessier and Dr. Salyer in 1972.

This extreme surgical procedure combined not only surgery involving deformity of the jaw but moving the orbits closer together, vertical repositioning and moving the orbits and other facial bones forward.

"The surgical rearrangement of the orbits is combined with the remaining facial sleleton so its component parts can be changed in any direction or a combination of directions," Dr. Salyer explained. Stabilization is obtained with the utilization of bone grafting, he added. According to Dr. Salyer, the complexity of craniofacial surgery is due to the variety of malformations, which involve both soft tissue and skeletal areas.

Included in the craniofacial abnormalities seen at the clinic from the relatively simple, such as cleft lip and palate, to the extremely complex 'monster-making' deformities, are approximately 50 different types. About 50 per cent of these, he said, defy known categories or classification systems.

But the members of the craniofacial team believe patients can best be helped to achieve the most in terms of the quality of their lives through the specialist team approach.

Says Dr. Sherrod: 'The application of this concept has to become more widespread as more and more people realize that the team approach is the valid way to attack these problems."