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ABSTRACT

Introduction: Cerebral palsy (CP) is a physically disabling condition affecting between 2 and 3 per 1000 live births and is believed to be the most common cause of severe physical disability in childhood. In addition to posture and movement disorders, these children have aggregate disorders such as limb use, communication, intellectual functioning, health, behavior, and social skills. The life of a family with a child with CP is transformed by obtaining a comprehensive diagnosis and treatment of their child's disorders.

Objective: To publicize the specialized medical approach promoted by the multidisciplinary team in caring for patients with CP through specialized care clinics.

Methodology: In these clinics, a coordinator shows to the consulting physician an average of 8 cases per month, offering clinical information and laboratory and cabinet studies of the patient, which the specialist physician assesses, and medical or surgical indications are offered according to the case. Between 1991 to 2020, care clinics were instituted; They have improved the health status of children with CP.

Keywords: cerebral palsy, malnutrition, orthopedic surgery, gastroesophageal reflux, pediatrics, primary care.

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ABSTRACT

Introduction: Cerebral palsy (CP) is a physically disabling condition affecting between 2 and 3 per 1000 live births and is believed to be the most common cause of severe physical disability in childhood. In addition to posture and movement disorders, these children have aggregate disorders such as limb use, communication, intellectual functioning, health, behavior, and social skills. The life of a family with a child with CP is transformed by obtaining a comprehensive diagnosis and treatment of their child's disorders.

Objective: To share publicize the specialized medical approach promoted by the multidisciplinary team in caring for patients with CP through specialized care clinics.

Methodology: In these clinics, a coordinator shows to the consulting physician an average of 8 cases per month, offering clinical information and laboratory and cabinet studies of the patient, which the specialist physician assesses, and medical or surgical indications are offered according to the case. Between 1991 to 2020, care clinics were instituted; They have improved the health status of children with CP.

Result: Since the founding of the first clinic, more than 5000 evaluations and more than 32,600 medical visits have been offered to patients with Cerebral Palsy from newborn to 18 years of age in specialized medical and surgical clinics.

Keywords: cerebral palsy, malnutrition, orthopedic surgery, gastroesophageal reflux, pediatrics, primary care.

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I. INTRODUCTION

Cerebral Palsy (CP) is a physically disabling condition, affecting between 2 to 3 per 1,000 live births, and is the most common cause of severe physical disability in childhood (1). In a study with an 8-year follow-up in children and adolescents with CP in Mexico, disorders of health integrity, muscle tone, structural state, use of limbs, communication, intellectual functioning, and mental health were found. Behavior and social skills in a range of 56 to 90% of cases (2). The life of a family with a child with CP is transformed by the challenge of obtaining a comprehensive diagnosis of their child's motor and related disorders. Spastic CP is the most common; In these children, hypertonic muscles and skeletal growth condition muscle-tendon and capsular contractures, bone deformities, conditioning more significant disability (3).

On the other hand, in this population, ocular mobility disorders occur in 66% (4). Gastrointestinal problems are a significant chronic problem in most children with CP, and a multidisciplinary approach can contribute to their well-being and quality of life (5); lack of appetite, hyper - salivation, eating dysfunction, and constipation are present in 25 to 38% of cases (6). Gastroesophageal reflux can influence its nutritional results (7), in which surgery offers nutritional and symptomatic improvement (8). Chronic pulmonary complications can include recurrent pneumonia, atelectasis, bronchiectasis, and chronic restrictive lung disease (9). The high prevalence of urinary tract infections in these

children supports effective physical therapy to achieve greater mobility and independence (10). Early provision of postural equipment plays a vital role in preventing hip subluxation/dislocation (11). The application of botulinum toxin has shown clinically significant, short-term improvements in the function of the upper extremities limbs (12).

The Institute Nuevo Amanecer A.B.P., a nonprofit organization with more than 43 years of experience dedicated to improving the quality of life of children and young people with cerebral palsy, has sought new ways to create prevention strategies and improve the care of these children and their families. For this reason, it has promoted and coordinated this clinical study, to continue promoting public policies and strategic alliances that promote the improvement of the quality of life of people with disabilities in the state of Nuevo Leon, Mexico.

II. OBJECTIVE

The objective of this manuscript is to share publicize the medical approach promoted by the multidisciplinary team in the care of patients with CP through specialized care clinics of different medical specialties.

III. METHODOLOGY

The Instituto Nuevo Amanecer A.B.P, is an outpatient care clinic. In 30 years, it has founded and offered systematized care through Specialized Care Clinics (SCC) to attend to this population's motor disorders and added problems; These services are offered within the same institution. The multidisciplinary team member refers the patient to the coordinator of a SCC, who offers a medical appointment to the mother or caregiver.

The team informs to parents the objectives of the respective clinic and the reason for the assessment to their son/daughter. The appointment includes detailed laboratory and X ray studies before their evaluation. The coordinator shows an average of 8 cases per month; she/he mentions the patient's symptoms in each clinic. The patient's medical history is reviewed, and interrogation and physical examination are carried out, and laboratory and cabinet studies results are analyzed. Finally, the pediatric neurologist offers the medical indications, requests complementary laboratory and X ray studies, and surgical if applicable. The social worker facilitates the performance of these procedures. There are agreements with different public and private hospitals to perform surgical procedures at no cost or minimal cost to the patient. In other cases, some foundations pay it directly to the hospital.

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IV. RESULTS

Profile of families. Almost half of the families are married couples: 47%. 28% Free union, 11% Single mothers 8%, Separated 6%, Divorced or widowed. Socio-economic level: 70% Medium-low, 17% Low. Medical Service: 48%. Right holders of Federal Insurance for low-income families, 48%, 43% have Health Ministry Insurance for families with formal employment, and 9% have medical insurance for employees of the education sector.

The Institute offers medical care, physiotherapy, occupational therapy, nutrition, early stimulation, regular care for high risk children, vaccinations, dental care, imaging services, postural care, and locomotion equipment, among others.

The institute has provided care to 25,961 patients in 43 years. The medical department consists of a Family physician, physiatrist, pediatric neurologist, and orthopedist and has offered more than 272,000 highly specialized medical visits and 888 medical-surgical procedures in the SCC.

V. ORTHOPEDIC CLINIC

Participants: Pediatric orthopedist, physiatrist, social worker.

Objective: To provide patients with CP with a highly specialized diagnosis and treatment of orthopedic problems and musculoskeletal deformations through a medical visit with the pediatric orthopedic doctor and physiatrist, offering them a medical, therapeutic, postural, and surgical treatment.

Procedure: The multidisciplinary team refers the patient to the Orthopedic Clinic, together the patient is evaluated, their radiological studies are reviewed, and treatment is scheduled. If postural care is required, he is referred to the Postural Care Clinic and is provided with postural equipment. When Botulinum Toxin or orthopedic surgery is required in local hospitals, physicians explain to parents or caregivers the needs and objectives of this treatment, and the social worker advises them. The most frequently encountered problems in this clinic are hip dislocation and spine deviations (scoliosis and kyphosis, among others). The most frequently implemented treatments have been: postural management, application of Botulinum Toxin in the lower limbs, multilevel tenotomy of the lower limbs, (adductor hip, hamstring, and Achilles tendon tenotomy). If orthoses are needed, they are custom-designed, manufactured by an external vendor, and delivered to the institution.

Two thousand and eight hundred medical visits and 902 orthopedic surgeries such tenotomies and osteotomies among others, have been performed. There have been more than six hundred applications of botulinum toxin, and more than 1900 references to postural management.

VI. OPHTALMOLOGY CLINIC

Participants: Pediatric ophthalmologist, Family physician, nurse, and social worker.

Objective: Offer a systematic preventive, palliative, and surgical evaluation and intervention in ophthalmological problems to patients with CP.

Procedure: When visual disorders are clinically detected in patients, they are referred by psychologists, therapists or teachers to this clinic. The Family physician introduces patients to an ophthalmologist at the same institution, and they are referred to a specialized clinic. This requests specialized studies and prescribe a treatment such as ophthalmic patches, lenses, or surgery; all families are advised and supported by the social worker. The surgeries are performed through a collaboration agreement with a local clinic and foundation. The most frequent treatments are strabismus corrections and the prescription of lenses for refractive defects.

There have been one thousand, nine hundred and sixty medical visits, 300 strabismus correction surgeries, 1500 visual refraction evaluations, and many lenses have been awarded.

VII. NUTRITION AND GASTROESOPHAGEAL REFLUX CLINIC

Participants: Pediatric Gastroenterologist, Family physician, nutritionist, and Social worker.

Objective: Assess CP patients with undernutrition, digestive, and feeding disorders.

Procedures: Physicians analyze the clinical history, nutritional status, and reason for the patient & #39;s visit. Laboratory studies such as (Hematic biometry, Biochemical Profile, Albumin Globulin Ratio, and Guayaco in feces), among others, are analyzed. Video-fluoroscopy (swallowing mechanism and esophagogram), scintigraphy, and ph-metry are also analyzed, depending on the case. The most frequent diagnoses in this clinic have been: Feeding disorders gastroesophageal reflux disease, undernutrition, aspiration, and constipation, among others. Each patient is offered a treatment that includes oral-motor therapy, antacids, proton pump inhibitors, prokinetics and laxatives, a hypercaloric and hyper protein diet, (depending on the case).

This clinic has carried out more than two thousand and three hundred nutritional visits and has given indications for more than 2000 oral-motor therapy, and dietetic supplements have been prescribed, and references to pediatric surgery when apply.

VIII. PEDIATRIC SURGERY CLINIC

Participants: Pediatrician surgeon, Family physician, and social worker.
Objective: Assess patients with CP who are referred to evaluate surgical interventions. Mainly of the digestive and urinary system, or in case of requiring hernioplasty procedures or corrections of congenital malformations.

Procedure: Patients determined to require a surgical approach during the gastroenterology or urology evaluation are evaluated in this clinic. These are showed by the Family physician to the pediatric surgeon, describing the clinical manifestations and analyzing their laboratory and cabinet studies. If surgery is required, this is performed in local hospitals.

Frequent cases referred to this clinic are: Nissen Fundoplication, Gastrostomy, Hernioplasty procedures, Orchidopexies, or Circumcisions. Oromotor therapy is also offered to patients with gastrostomy due to an eating disorder, and indications to the primary caregiver for the use of gastrostomy and gastric button. When appropriate and linked to evolution, gastrostomy closure is also performed.

Since its foundation, more than one thousand and six hundred medical visits and 140 surgeries of different kinds have been performed (gastrostomy button, gastrostomy closure, Nissan surgery, and others).

IX. RESPIRATORY PROBLEMS CLINIC

Participants: Otolaryngologist, pediatric pneumonologist, Family physician, and social worker.

Objective: To offer patients with CP a highly specialized diagnosis and treatment in the case of chronic or recurrent respiratory diseases, as well as hearing loss.

Procedure: The multidisciplinary team detects and refers patients with recurrent respiratory problems for evaluation. The Family physician assesses the patient and requests the necessary studies. (Hematic Biometry, Paranasal Sinus Rx, Thorax Tele). The patient is referred to the otorhinolaryngologist, who assesses the patient, analyzes his clinical data, x-rays, and laboratory and office tests. After evaluation, some complementary studies are requested if necessary, such as scintigraphy, and ph-metry; after its analysis, treatment is prescribed. The most frequent diagnoses in this clinic have been: sinusitis, sinubronchial syndrome, bronchitis, pneumonia, otitis media, allergic rhinopharyngitis, bronchial aspiration, and adenoid hypertrophy. The most frequently prescribed medications have been antibiotics, antihistamines, anti-inflammatories,bronchodilators, and immuno-modulatory drugs.

The most frequent surgeries have been:

Tonsillectomy and myringotomy. In case of hearing loss, studies such as auditory evoked potentials and tympanometry, among others, are requested after evaluating the patient. Support are offered to carry out these studies, to obtain medications, hearing aids, and perform surgeries by the support of social worker.

The Family physician follows up and makes a new appointment at the clinic to see the results of studies and treatment.

This clinic has performed more than one thousand eight hundred medical visits, more than 100 surgical procedures as tonsillectomies and adenoid hypertrophy, myringotomies, more than 200 evaluations of hearing loss, and 150, auditory evoked potentials, among others.

X. CLINIC OF UPPER LIMBS

Participants: Plastic surgeon with a sub-specialty in the upper limb, occupational therapist, physiatrist, and social worker.

Objective: To evaluate patients with CP who have spasticity or hand/arm deformities.

Procedure: Cases with spastic upper limbs are referred by the multidisciplinary team to the department of family medicine. The patient is evaluated by the upper limb clinic coordinator occupational therapist and is classified according to his manual abilities and degree of spasticity, and radiological studies are carried out necessary for the assessment. During the visit, the participation in activities of daily living is analyzed to design functional goals in their treatment, including botulinum toxin application or surgery, with the social worker's support. After these procedures, a new evaluation of the manual abilities of the patients is carried out, and the necessary modifications are made to the occupational therapy treatment plan. In cases where splints are required; these are manufactured in a personalized way in the same institution.

This clinic has offered more than one thousand and two hundred medical visits, and also applied more than 6 hundred botulinum toxin specialy in hands and arms, and provided of more than 600 upper limb splints.

XI. POSTURAL MANAGEMENT CLINIC

Participants: Physiatrist, occupational therapist, an expert in postural management, biomedical engineer, and social worker.

Objective: To carry out a postural diagnosis to the patient and offer the design and manufacture of personalized postural aids.

Procedures: Patients with postural management disorders are referred to the Postural Care Clinic by the multidisciplinary team. Expert doctors and therapists evaluate them with the Chailey Approach Technique in prone and supine decubitus, sitting and standing, and a Chailey bed, modular or body contour seat, and stabilizer. The seats are inserted in conventional or power wheelchairs. Parents or caregivers receive the social worker's support from local organizations or foundations for their acquisition.

More than 3,000 postural management evaluations and the corresponding manufacture of the personalized postural management equipment have been carried out according to each patient needs, and more than 1200 equipments have been manufactured in the institution.

XII. UROLOGY CLINIC

Participants: Urologist, Family physician, nurse, and social worker.

Objective: To diagnose and take care of patients with CP and urological disorders.

Procedures: Patients with urination disorders, signs of urinary infection, and or at/the beginning of a sphincter control program are referred to this clinic by the multidisciplinary team. Before the examination, a general urine test is performed. The medical history and signs of urological disorders are analyzed during the evaluation, a physical examination focused on detecting urinary tract and genital malformations.

At the end of the evaluation, studies are requested, such as voiding cystourethrogram, urological ultrasound, and urine culture. As applicable, which are carried out with the social worker's support and medical or surgical treatment. A medical follow-up is carried out at the end of the procedure until the urinary problem is resolved. In the case of a urinary sphincter control program, nursing follow-up is offered to the patient once urological pathology has been ruled out. The most frequent diagnoses are urinary tract infection, cryptorchidism, phimosis, and congenital malformations.

This clinic is the most recent and has granted more than 500 urological visits.The most frequent pathologies detected have been chryptorchidism, and phymosis.

XIII. PNEUMOLOGY CLINIC

Participants: Pulmonologist, family doctor, and social worker.

Objective: Provide patients with a highly specialized diagnosis and treatment in chronic and recurrent respiratory diseases through a specialized medical consultation, thus increasing their quality of life of these children.

Procedures: The multidisciplinary team detects and refers patients with respiratory problems to the Medical Department. They request laboratory studies such as blood counts and cabinet studies such as chest teleradiography and polysomnography.

The treatment plan may include medical or surgical treatment and, if required, referral to another specialty or hospital .In this CSS more than 500 medical visits have been made, Frequent diagnoses in this clinic are: recurrent pneumonia secondary to aspiration due to gastroesophageal reflux disease or allergies, bronchial hyperreactivity, laryngomalacia, and decreased ventilatory capacity secondary to scoliosis. Moreover, treatment includes antibiotic therapy, inhalation therapy, and percussive therapy.

XIV. SPASTICITY CLINIC

Participants: Pediatric neurologist, physical therapist, and social worker.

Objectives: To provide patients with a highly specialized diagnosis and treatment of spasticity problems and contribute to obtaining more satisfactory result in their rehabilitation.

Procedures: The patient level of spasticity and current weight are considered, and gross motor function classification system, (GMFCS).

They are evaluated with Modified Ashworth Scale, (MAS), and analyzing Reimer index.

The Coordinator presents the case to the consulting physician. The most frequently used studies are pelvic X rays to assess hip subluxation or dislocation.

The most frequent pathologies detected have been contractures of upper and lower limbs.

Treatment generally consists of administering muscle relaxants such as oral baclofen, the application of botulinum toxin, physical therapy, hydrotherapy, upper and lower limbs splints, and reference to postural management and/or orthopedic surgery. In this clinic, more than 340 patients have been assessed and more than 80 botulinum toxin have been applied with the support of social workers.

XV. DISCUSSION

In countries where few organizations provide highly specialized and rehabilitative care to children and young people, patients with CP and their families require multidisciplinary care coordinated with inter-institutional links that provide them with comprehensive care.

Laboratory and office studies, medications, postural aids, and surgeries necessary to provide this care can be facilitated through agreements with local hospitals and foundations. Therefore, we urge organizations that serve children and youth with CP to use this care methodology to provide greater well-being to these children and their families.

Some institutions in countries such as England (13) and the USA (14) use similar models of specialized care clinics for the comprehensive approach to patients with CP.

XV. CONCLUSIONS

The SCC have had a satisfactory result, for over 27 years, more than 15000 evaluations have been provided, and an average of 24 surgeries and procedures per year for children with CP from low-income families of northeastern Mexico. The results have been reflected in improving the patients' physical well-being attended.

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