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International Telemedicine Consultations for Neurodevelopmental Disabilities

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Abstract

Background: A telemedicine program was developed between the Children's National Medical Center (CNMC) in Washington, DC, and the Sheikh Khalifa Bin Zayed Foundation in the United Arab Emirates (UAE). A needs assessment and a curriculum of on-site training conferences were devised preparatory to an ongoing telemedicine consultation program for children with neurodevelopmental disabilities in the underserved eastern region of the UAE. **Materials and Methods:** Weekly telemedicine consultations are provided by a multidisciplinary faculty. Patients are presented in the UAE with their therapists and families. Real-time (video over Internet protocol; average connection, 768 kilobits/s) telemedicine conferences are held weekly following previews of medical records. A full consultation report follows each telemedicine session. **Results:** Between February 29, 2012 and June 26, 2013, 48 weekly 1-h live interactive telemedicine consultations were conducted on 48 patients (28 males, 20 females; age range, 8 months–22 years; median age, 5.4 years). The primary diagnoses were cerebral palsy, neurogenetic disorders, autism, neuromuscular disorders, congenital anomalies, global developmental delay, systemic disease, and epilepsy. Common comorbidities were cognitive impairment, communication disorders, and behavioral disorders. Specific recommendations included imaging and DNA studies, antiseizure management, spasticity management including botulinum toxin protocols, and specific therapy modalities including taping techniques, customized body vests, and speech/language and behavioral therapy. Improved outcomes reported were in clinician satisfaction, achievement of therapy goals for patients, and requests for ongoing sessions. **Conclusions:** Weekly telemedicine sessions coupled with triannual training conferences were successfully implemented in a clinical program dedi-

cated to patients with neurodevelopmental disabilities by the Center for Neuroscience at CNMC and the UAE government. International consultations in neurodevelopmental disabilities utilizing telemedicine services offer a reliable and productive method for joint clinical programs.

Key words: telemedicine, telehealth, technology, distance learning, education

Introduction

Telemedicine is an innovative technology that facilitates international healthcare, especially in underserved areas.¹ Telemedicine consultations can result in improved clinical outcomes and reduced costs and, furthermore, reduce morbidity, inappropriate care, travel expenses, and patient transfers.² These benefits are even more useful for specialty than primary care.² As a result of increasing accessibility to medical care via telemedicine, patients can undergo earlier treatment with improved adherence.³ Neurology and psychiatry are considered optimal specialties for live interactive telemedicine based on the substantial amount of verbal patient interaction and subsequent assessment.⁴ Live interactive "teleneurology" additionally requires few deviations from in-person assessments of verbal and nonverbal communication, body language, and motoric behavior.⁴ Additionally, healthcare providers in underserved areas can benefit through distance learning and training.⁵

A collaborative project between the Center for Neuroscience and Behavioral Health at the Children's National Medical Center (CNMC) in Washington, DC, and the Sheikh Khalifa Bin Zayed Foundation in the United Arab Emirates (UAE) was created to provide clinical services and professional training in neurodevelopmental disabilities for the underserved eastern regions of the UAE. This included regular training conferences for professionals and weekly telemedicine consultations for children and families with neurodevelopmental disabilities. We report our clinical and technical experience of the first 16 months of this program.

Materials and Methods

Weekly telemedicine consultations are provided by a neurodevelopmental team from the CNMC for families and clinicians based in the eastern region of the UAE. This is a geographically underserved region with minimal services for individuals with neurodevelopmental disabilities, and patients in this region do not have easy access to the more established western centers, including Abu Dhabi and Dubai. The Sheikh Khalifa Foundation requested provision of services to the eastern population. The telemedicine consultation team consists of representation for the clinical disciplines of pediatric

neurology, genetics, physical medicine and rehabilitation, physical therapy, occupational therapy, speech and language pathology, and psychology. The international medicine department provided operational support. The program adhered to the core administrative, clinical, and technological standards of the American Telemedicine Association.⁶

The families and patients are presented by a group of clinicians located in the Fujairah Rehabilitation Center for Disabled or the Dibba Rehabilitation Center for Disabled in Fujairah and Dibba, UAE, respectively. There are bilingual members of the team in both locations for English and Arabic translation. Telemedicine conferences are scheduled for clinical assessments of patients and families selected by the UAE clinicians. Medical records are reviewed prior to the telemedicine session, and each session is followed by a full consultation report including diagnostic formulation and specific treatment recommendations. From each report, key diagnostic notes and corresponding areas of impact were extracted and assembled into the categories displayed in *Tables 1–3*.

Our telemedicine technical team managed installation of equipment in the UAE. Conference rooms that allowed for direct patient consultation and education were established in Dibba and Fujairah. Cisco (San Jose, CA) Tandberg Codecs were installed (model C90 in Fujairah and model C60 in Dibba) and allowed for multiple inputs including a 1080 pixel video camera. Videoconferences were carried out using Internet protocol with most connections taking place at 768 kilobits/s. Security was maintained via firewalls on both ends. A blended CYVIZ wall, video processor, and projector were installed along with software via a multitouch monitor for easy control by the local teams in Fujairah and Dibba. High-fidelity audio equipment was also installed. After installation, day-to-day maintenance of the UAE site was turned over to the local team. However, the CNMC's technical team remained directly involved for 24/7 support, including direct supervision of each live videoconference. The CNMC team primarily participated in videoconferences from a small conference room using a Cisco Tandberg Edge 95.

Table 1. Primary Diagnoses

PRIMARY DIAGNOSIS	NUMBER OF PATIENTS (N= 48)
Cerebral palsy	15
Global developmental disorder	12
Autism	9
Congenital anomalies	7
Neurogenetic disorders	6
Epilepsy	5
Neuromuscular disorders	4
Systemic disease	2

Table 2. Common Comorbidities

COMMON COMORBIDITY	NUMBER OF PATIENTS (% OF TOTAL)
Cognitive impairment	32 (67%)
Communication disorders	32 (67%)
Behavioral disorders	16 (33%)

A needs assessment was performed during two screening trips to review clinical facilities, with use of interviews and surveys to ascertain common diagnoses, available services, and service gaps. Subsequently, a curriculum was devised to provide on-site week-long training courses. Three annual courses were scheduled over a 3-year period with curricula dedicated to the on-site participating educators and therapists.

Results

Forty-eight weekly 1-h live interactive telemedicine sessions were conducted over a 16-month period, between February 29, 2012 and June 26, 2013. There were consultations on 48 patients (28 males, 20 females; age range, 8 months–22 years; median age, 5.4 years). The distribution of primary diagnoses is shown in *Table 1*; some patients were given multiple primary diagnoses and are counted more than once. Specific diagnoses that fell within these primary categories were as follows: neurogenetic disorders (cobalamin C deficiency, Down's syndrome, Rett's syndrome, glutaric aciduria type I, Phelan-McDermid's syndrome [22q13del], Sanfilippo type B syndrome), congenital anomalies (spina bifida, Pierre Robin's syndrome, Dandy-Walker's malformation), neuromuscular disorders (spinal muscular atrophy type II, limb-girdle muscular dystrophy), systemic disease (congenital heart disease), and epilepsy (including West's syndrome). Additionally, common comorbidities among the patients are shown

Table 3. Specific Management Recommendations

SPECIFIC MANAGEMENT RECOMMENDATIONS	NUMBER OF PATIENTS
Speech therapy	26
DNA studies	23
Orthotics	18
Imaging studies	14
Botulinum toxin	9
Behavioral therapies	8
Referral for orthopedic surgical procedures	6
Antiseizure medication management	5
Kinesiotaping	3

in *Table 2*. Specific management recommendations are indicated in *Table 3* and included a range of diagnostic (imaging and laboratory), therapeutic (medical and rehabilitative), and procedural (botulinum toxin injections, orthopedic surgical) interventions.

The recommendations have been received with improved outcomes, including clinician satisfaction for training, reported attainment of therapy goals for patients, and requests for ongoing sessions. Based on the telemedicine sessions, 1 patient was transferred and hospitalized at the CNMC in the United States for further management of spasticity and epilepsy.

A series of visits was utilized to accomplish the initial needs assessment phase. Four regional centers in the eastern region of the UAE were visited: Fujairah, Dibba, Korfakkan, and Sharjah. Triannual training conferences were scheduled over a 3-year period, during which a team of specialists from CNMC travel to the Fujairah Center for Children with Disabilities and teach a group of 60–100 participants comprising special educators, child psychologists, and physical, occupational, and speech and language therapists. The sessions are held in English with simultaneous Arabic translation. All teaching materials, including syllabi and slides, are presented bilingually.

The teaching conferences had preselected themes of emphasis based on the needs assessment and included cerebral palsy, au-

tism, spinal cord injury, genetics, spina bifida management, spasticity diagnosis and management, behavior modification therapy including applied behavioral analysis for autism, and specific speech and language therapy modalities dedicated to individuals with autism spectrum disorder. Special skills workshops have been provided with modalities including botulinum toxin protocols, kinesiotaping, and customized body vest fitting. An example of the curriculum for a single week is demonstrated in *Table 4*.

Discussion

International consultations in neurodevelopmental disabilities utilizing telemedicine services offer a reliable and productive method for joint programs with clinically effective sessions and improved outcomes. State-of-the-art technology provides clinical and interdisciplinary expertise and experience that may not be available on-site to patients and families. The higher level of service in diagnostic and therapeutic recommendations was particularly important in the complex cases common to this program. Video and audio transmission simulated the typical patient–doctor experience more effectively than a conference call, e-mail, or online consultation and served to mutually build confidence throughout the consultation process.

Table 4. Conference Schedule Year 2 (September 2012–September 2013) Training Overview

DATE, TOPIC	COMPETENCY BUILDING	DIDACTICS/BREAKOUT	LEARNER ACTIVITY REVIEW	HAND-ON CLINICAL
December 2012 (Thursday, December 6–Friday, December 14), Skills: Spasticity, Language Workshop	<ul style="list-style-type: none"> • Introduction to Genetics: Family History Is Important • Clinical Correlation of Down’s Syndrome: History, Current, and Future • Hanen Learning Language and Loving It Workshop Parts 1, 2, 4, and 6 	<ul style="list-style-type: none"> • Advanced Spasticity Management • Highlights of Cerebral Palsy • Promising Breakthroughs in Research, Knowledge, and Practice 	<ul style="list-style-type: none"> • The Importance of Positioning for Optimization of Musculoskeletal Alignment and Function • Therapeutic Approaches to Improve Position and Function • Hanen Learning Language and Loving It Workshop Parts 3 and 5 	<ul style="list-style-type: none"> • Patient Assessments and Reviews • Telemedicine Weekly Clinical Consultation Online Resources
March 2013 (Thursday March 21–Friday March 29), Skills: ABA, Sensory Integration	<ul style="list-style-type: none"> • ABA Workshop Parts 1, 3, and 4 • Hanen Learning Language and Loving It Workshop Part 2, Sessions 1 and 3 	<ul style="list-style-type: none"> • Sensory Processing Strategies in the Classroom • Therapeutic Interventions: Kinesiotaping • Therapeutic Interventions: Bracing and Splinting • Therapeutic Interventions: Positioning and Seating 	<ul style="list-style-type: none"> • ABA Workshop Parts 2 and 5 • Hanen Learning Language and Loving It Workshop Part 2, Sessions 2 and 4 	<ul style="list-style-type: none"> • Patient Assessments and Reviews • Telemedicine Weekly Clinical Consultation Online Resources
June 2013 (Thursday, June 13–Friday, June 21), Autism/ABA, Concussion, Language Therapy	<ul style="list-style-type: none"> • ABA Workshop Parts 1 and 3 • Hanen Learning Language and Loving It Workshop Part 2, Sessions 1, 3, and 4 • Concurrent Therapy Sessions 	<ul style="list-style-type: none"> • Health and Fitness Programs for Children with Special Needs • Concussions and Children with Special Needs • Neurodevelopmental Treatment in the Classroom • Autism Spectrum Disorders: A Review of Recent Literature 	<ul style="list-style-type: none"> • ABA Workshop Parts 2 and 4 • Hanen Learning Language and Loving It Workshop Part 2, Sessions 2 and 5 	<ul style="list-style-type: none"> • Patient Assessments and Reviews • Telemedicine Weekly Clinical Consultation Online Resources

ABA, applied behavioral analysis.

Specific management recommendations were well received and required coordination with local services on the ground. Ongoing feedback regarding management of antiepileptic drugs and dietary/metabolic requirements were both areas that were recurring themes with concentrated emphasis in selected patients. Dosing and selection of antiepileptic drugs in particular, as well as more detailed management of metabolic disorders, such as protein restriction and vitamin supplementation in the organic acid disorders, were examples of highly specific therapeutic plans. Informational materials were regularly sent, including methods of measurement for fitting of body vests or specifications for equipment modalities such as orthotics. The child psychology consultant commonly recommended behavioral therapy. The most consistent recommendation was to restrict television and other screen time, especially for children having socialization deficits. Excessive childhood screen time is associated with poor educational achievement,⁷ consistent with the American Academy of Pediatrics guideline for imposing screen time limits on children, and supports the psychological management recommendation of cutting screen time.⁸

In conjunction with telemedicine consultations, the CNMC team provided regular leadership training conferences in the main UAE facility for the eastern region, located in Fujairah. These conferences educate clinicians and teachers for diagnosing, treating, and providing therapy to patients. Follow-up assessments have also been added during the telemedicine sessions to provide ongoing recommendations. We anticipate continuing both the telemedicine and on-site teaching programs. Plans have been made to sustain these activities, which are reimbursed through the UAE Shaikh Khalifa Foundation. In developing or underserved areas, these sampled populations can serve to provide a representative population for planning and developing additional medical services and facilities.

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Disclosure Statement

No competing financial interests exist.

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