Extension for Community Healthcare Outcomes Uruguay: A New Strategy to Promote Best Primary Care Practice for Autism

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Abstract

Introduction. In Uruguay, the special care required for children with neurodevelopmental disorders presents difficulties including lack of access to specialists and rehabilitation services. Project ECHO (Extension for Community Healthcare Outcomes) connects primary care clinicians from remote areas to specialists to enable them to treat complex conditions through ongoing education and mentoring. *Objective.* To share the experience of the ECHO Autism program during the first 2 years of implementation. *Methods.* Analysis of ECHO Autism clinics from June 2015 to June 2017 including clinical cases presented participants' self-perception of changes in skills and competences. *Results.* Twenty clinical cases were presented: mean age 4.5 years; 15 were males; and 17 with medical and psychiatric comorbidities. After ECHO Autism implementation, a statistically significant improvement in participants' self-perception of skills and competences was observed. *Conclusions.* ECHO Autism in Uruguay is a meaningful approach to autism care and offers improved access to best practice care.

Keywords

autism, project ECHO, training, primary care practices

Introduction

Project ECHO (Extension for Community Healthcare Outcomes) is a collaborative model of continuing medical education and mentoring. Through regularly scheduled videoconference sessions called teleECHOs, specialists at academic centers share their experience and knowledge with primary care clinicians in remote areas. The case-based learning enables them to treat patients with complex conditions in their own communities. The ECHO model is not "traditional telemedicine" where the specialist assumes care of the patient, but instead is a guided practice model where the participating providers retain responsibility for managing their patients. The ECHO model increases both capacity and access to specialized treatment in rural and underserved areas.[1] Project ECHO was founded in 2003, by Dr Sanjeev Arora, a Distinguished Professor of Medicine at the University of New Mexico Health Sciences Center (UNMHSC), as a response to the needs of patients with hepatitis C virus in New Mexico. In 2011, ECHO published a prospective cohort study in the *New England Journal of Medicine*, to prove that treatment for hepatitis C virus by primary care clinicians using the ECHO model is as safe and effective as treatment by specialists at an academic medical center.[1-8]

Since its creation, more than 200 partners at academic medical centers and other sites have replicated ECHO across the United States and around the world. The ECHO model has also grown to cover more than

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100 complex conditions such as HIV, tuberculosis, chronic pain, endocrinology, and behavioral health disorders.[5] In 2014, the Universidad de la República and Project ECHO at UNMHSC signed an agreement that allowed the implementation of Project ECHO in Uruguay led and coordinated by Professor Henry Cohen. Since the beginning of this program, teleECHO sessions have been held on hepatitis C, frequent liver diseases, palliative care, HIV, cardiac failure, neurorehabilitation, autoimmune diseases, family medicine, cervical cancer, and autism spectrum disorders (ASD).[9]

Uruguay provides universal health care through an Integrated National Health System with public and private providers. Although in recent years this system has contributed to improving the health of children,[10] the special care required for children with neurodevelopmental disorders presents difficulties including delays in early diagnosis and lack of access to autism specialists and rehabilitation services.[11] Children with developmental concerns and/or autism often have long waits to see a specialist and to receive treatment by speech language therapists and occupational therapists. In order to improve the outcomes of patients with ASD, a multidisciplinary team including pediatricians, neuro-pediatricians, and child psychiatrists started the ECHO Autism program in 2015.

ASD is a developmental disorder that affects communication and behavior. In general, the symptoms appear in the first 2 years of life. According to the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), children with ASD have difficulty with communication and social interaction and restricted interests and repetitive behaviors. Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience.[12,13] The prevalence of these disorders has increased in recent years.[14,15] Early diagnosis and treatment is important as proper care can reduce individuals' difficulties while helping them learn new skills and make the most of their strengths. Quality interventions with a multidisciplinary approach are also necessary to help improve the prognosis. Both diagnosis and management of ASD require a high degree of clinical expertise, which is not freely available even in developed countries and practically nonexistent in low- and middle-income countries.[13-16]

Children with ASD and their families have greater and specific health care needs.[17,18] Unmet medical needs lead to challenging behavior and poorer family quality of life. Therefore, programs such as Project ECHO that support primary care professionals in providing best practice medical care are necessary.[19]

To address the gap in care, Drs Kristin Sohl and Micah Mazurek from the University of Missouri developed an ECHO model for ASD with curriculum based on the Autism Treatment Network Model as part of Autism Speaks and Autism Intervention Research of Physical Health Network. ECHO Autism clinics were conducted twice per month, for 2 hours per clinic with a specific focus on training in screening and identification of ASD and management of common medical and psychiatric comorbidities. The participants were primary care providers from across the state of Missouri. After the first 6 months of this experience, participants reported statistically significant improvements in self-efficacy of practitioners across all domains of medical care for children with ASD studied and knowledge of and referral to appropriate resources.[19]

This article shares the experience of the ECHO Autism program in Uruguay during the first 2 years of implementation, including the characteristics of the analyzed patients and professionals who participated, as well as the evaluated impact of self-perception of participants regarding their skills and competences.

Methods

Twenty sessions of the ECHO Autism clinic from June 12, 2015, to June 9, 2017, were included in this descriptive retrospective study. The general objective of the ECHO Autism program is to create a community of practice for professionals caring for individuals with autism. This community of practice includes primary care clinicians, specialists in autism, and other allied health professionals. ECHO Autism utilizes virtual videoconferencing software to eliminate geographic and travel barriers experienced with more typical professional training methods. The specific objective of the ECHO Autism clinic is to strengthen the skills and confidence of these professionals and to improve autism diagnosis and therapeutic approach. Curriculum was developed to support these objectives and included the following topics: diagnostic criteria, etiology, screening and diagnostic tools, medical and psychiatric comorbidities, and treatments. The ECHO Autism clinics were conducted using basic, widely available videoconferencing technology. Technology requirements by participants included access to the Internet and a forward-facing video camera. The teleECHO clinics were held once a month and lasted 1 hour per session. The expert panel included faculty from the School of Medicine at the Universidad de la República, specifically 2 pediatricians, a neuro-pediatrician, and a child psychiatrist. The expert panel was located at an academic medical center (Pereira Rossell Hospital) in Montevideo, the capital city. Participants in ECHO Autism clinics were primary care professionals, with the majority being pediatricians

from across Uruguay. Their participation was voluntary. Recruitment strategies included social and traditional media, state-wide primary care association listservs, and word-of-mouth strategies. During ECHO Autism clinics, primary care professionals were connected to one another and to the expert panel and gained knowledge and confidence through repeated case discussions.

Each clinic consisted of clinical case presentations with specific questions by primary care providers, discussion among all participants, and recommendations from the expert panel. Most sessions incorporated a brief didactic focusing on best-practice care of children with ASD.

Experts serve as mentors and colleagues sharing their medical knowledge and expertise with primary care clinicians. Each teleECHO clinic operates as a "knowledge network" in which participants engage in case-based learning. Practitioners in ECHO Autism maintained the responsibility for the care of their patients, building skills through guided practice, and collaborative learning.[2,19]

Ethical approval was obtained from the hospital medical ethics committee. All identities of both patients and participants were kept confidential.

Parents and patients did not participate directly in teleECHO clinics. Parental informed consent was required prior to the case presentations and data confidentiality was protected during teleECHO clinics.

Three groups of variables were analyzed to describe characteristics of the ASD teleECHO clinics: (1) patients (clinical cases presented), (2) participants (primary care professionals), and (3) self-perception of changes in skills and competences of participants. Participants who attended at least 50% of the ASD teleECHO clinics annually were a part of the study.

Related to patients, variables included the following: age, sex, place of residence, health provider, first symptoms, age at time of suspicion, comorbidities, treatment, and reasons for presentation in ECHO.

Related to participants, variables were the following: age, sex, place of residence, place of work, and previous ASD training. As previous ASD training criteria considered included conferences, workshops, coursework contents, and residency rotation.

Provider self-perception about changes of skills and competences in diagnosis and management of children with ASD was assessed at pretest and posttest using an anonymous web-based survey. The self-perception of skills and competences was measured from 12 indicators that cover the following domains: (1) identifying neurodevelopmental deviances before 3 years old, (2) ASD screening and diagnosis, (3) diagnosis and management of comorbidities, (4) differential diagnosis, (5)

resources for a comprehensive approach, and (6) transfer of knowledge to the local medical team. Items were rate on a 7-point Likert-type scale: (1) no skill/competence, (2) vague skills/knowledge, (3) mild skills/knowledge, (4) average related to peers, (5) competent, (6) very competent, and (7) expert.[1] This questionnaire was applied at the end of the first year of the beginning of the Autism Program.

Data Analysis

To describe the characteristics of patients and participants, mean, range, and frequencies were used. In the analysis of self-perception changes of skills and competences of participants a t test was used, and a $P < .05$ was considered statistically significant. Internal consistency of Likert-type scale using Cronbach's α before ECHO Autism was 0.93, and after ECHO Autism it was 0.92. Data resources were teleECHO clinic records and patient pre-coded files.

Results

During the study period, 20 ECHO Autism clinics were conducted. Forty-five participants were connected in at least 50% of the sessions. The annual mean of connected centers was 9 (range 4-12) in the first year, and 23 (range 12-33) in the second year.

The median age of participants was 42 years (range 29-65). Most participants were female (n = 43), from the capital city Montevideo (n = 38). They also included private health providers (n = 27) and pediatricians (n = 36). Of the 45 participants, 10 had previous ASD training (Table 1). The number of participants fluctuated in each session, with a minimum of 10 and a maximum of 55 participants per ECHO Autism clinic.

Twenty clinical cases were presented in the ECHO Autism clinics. Mean age was 4 to 5 years (range 1-12). Most patient cases presented were male (n = 15), from Montevideo (n = 13), and from public health providers (n = 11). The first symptoms were language delay (n = 7), social interaction disturbances (n = 6), stereotypes (n = 5), and sleep disorders (n = 2). Median age at time of suspicion was 18 months (range 12-60). Seventeen patients presented with comorbidities in addition to autism. Seven of the 17 cases presented with 2 or more medical comorbidities. Medical comorbidities included sleep disorders, gastrointestinal problems, and epilepsy. Psychiatric comorbidities included anxiety, irritability, hyperactivity, and intellectual disability.

Twelve patients were treated with psychopharmacological treatments and 19 with psychoeducational treatments and/or specific rehabilitations (language/speech,

Table 1. Characteristics of Participants ECHO ASD (N = 45).

	Number	Percentage
Sex		
Female	43	95
Place of residence		
Capital city	38	84
Rest of the country	7	16
Health provider		
Public	18	40
Private	27	60
Specialty		
Pediatrician	36	80
Child psychiatrist	6	13
Psychologist	2	4.5
Other	1	2.5
Previous ASD training	10	22
Child psychiatrist	6	
Psychologist	2	
Pediatrician	2	

Abbreviations: ECHO, Extension for Community Healthcare Outcomes; ASD, autism spectrum disorder.

Table 2. Characteristics of Patients ECHO ASD (N = 20).

Age at time of suspicion, mean (range)	18 Months (12-60)	
	Number	Percentage
Reason for presentation in ECHO		
Difficulties in diagnosis	4	20
Difficulties in therapeutic approach	16	80
Male	15	75
Capital city	13	65
Rest of the country	7	35
Health provider		
Public	11	55
Private	9	45
Comorbidities, n = 17		
Medical		
Sleep disorders	7	41
Gastrointestinal problems	3	18
Epilepsy	5	30
Psychiatric		
Anxiety	1	6
Irritability	5	29
Hyperactivity	2	12
Intellectual disability	3	18
Treatments, n = 19		
Pharmacological	12	60
Nonpharmacological	19	100
Language/speech	9	47
Psychomotor	9	47
Neurocognitive	2	10.5
Parent training	5	26
Pedagogical	4	21
Gluten/casein free diet	2	10.5
Art therapy	1	5

Abbreviations: ECHO, Extension for Community Healthcare Outcomes; ASD, autism spectrum disorder.

psychomotor, neurocognitive, pedagogical). Reasons for presentation to ECHO Autism included the difficulties in therapeutic approach with focus on comorbidity management (n = 16) and diagnosis (n = 4; Table 2).

Thirty-eight participants answered the survey. After ECHO Autism implementation, a statistically significant improvement in participant self-perception of skills and competences was observed (Table 3).

Discussion

During the first 2 years of implementation of the ECHO Autism program in Uruguay, a group of primary care providers interacted regularly to improve their clinical practices related to implementing best practice care for individuals with autism. It is well established that children with autism have considerable unmet medical needs. This gap results in poorer outcomes for this population. Therefore, the objective of ECHO Autism is to create a virtual community to share mentor primary care providers through their own cases and deliver best practices for individuals with autism regardless of their ability to physically access developmental medicine specialists. Since inception, ECHO Autism participation in Uruguay has grown and includes professionals from public and private medical care centers. In Uruguay, professionals from these sectors are often siloed resulting in suboptimal dissemination of best practices and care for patients. By bridging the gap between specialty providers and primary providers and between private and public medical providers, ECHO Autism clinics facilitated the demonopolization of knowledge, facilitating the access of medical expertise from academic centers to remote areas.[1,2,4-9]

Considering that the ECHO model promotes collaborative learning based on the discussion of complex clinical cases, it is a good strategy to enhance professional skills and competences. To accomplish this, it is necessary to work in conjunction with professionals of other disciplines.[9,20] Project ECHO Uruguay is centralized in the capital (Montevideo). Like the population, the majority of medical providers are located in this large city. The inadequate distribution of pediatricians in the country represents an obstacle,[21] and the ECHO Autism program is actively working to broaden this

Table 3. Self-Perception Changes of Skills and Competences of Participants (N = 38).

Skills and/or Competences	Before ECHO ASD, Mean (SD)[a]	After ECHO ASD, Mean (SD)[a]	P
Identify neurodevelopmental deviances	3.42 (1.11)	4.84 (0.77)	<.01
ASD diagnosis	3.26 (1.09)	4.60 (0.81)	<.01
Comorbidities diagnosis	2.78 (1.07)	4.26 (1.26)	<.01
Differential diagnosis	2.76 (1.06)	4.24 (1.26)	<.01
Resources for a comprehensive approach	2.79 (1.13)	4.47 (1.04)	<.01
Pharmacological treatments	2.42 (1.06)	3.60 (1.08)	<.01
Transfer knowledge to local teams	2.60 (1.42)	4.34 (1.05)	<.01
Identify family needs	3.11 (1.18)	4.53 (0.89)	<.01

Abbreviations: ECHO, Extension for Community Healthcare Outcomes; ASD, autism spectrum disorder.
[a]Standard deviation Cronbach's α for the 8 Before ECHO ASD items = .93, and Cronbach's α for the 8 After ECHO ASD items = .92.

community by including a variety of professionals across more rural Uruguay. We are encouraged that the model was effective in the current study participants and anticipate dissemination of the model throughout the country. At the end of the first year of ECHO Autism program implementation, a statistically significant improvement in participant self-perception of skills and competences in all fields evaluated was observed. These results show that ECHO Autism is useful in strengthening health care provider knowledge of autism.

However, the mean of the score obtained in the different domains explored after training was less than 5, so the participants did not reach the "competent" level. This underscores the need for ongoing subspecialist support for primary care providers as they continue to gain expertise through the ECHO Autism community of practice.

Although the results of this study highlight incremental growth in provider self-efficacy for diagnosis and treatment of children with ASD, the impact on individuals with autism and their access to best practice care and individual outcomes improvement was not directly assessed.

We are encouraged by the content of the clinical cases focusing on common medical or psychiatric comorbidities as these conditions are critical unmet needs for families. With the high incidence of comorbidities like gastrointestinal and sleep disorders, and epilepsy, knowledge and adequate management of these pathologies improves the prognosis and quality of life of ASD children and their families.[20]

During the 2-year study utilizing the ECHO model, we were able to contribute to the resolution of 20 clinical cases, making recommendations to improve care practices and help teams implement more effective treatments. One of the main objectives of the ECHO Autism clinics is to contribute to early ASD diagnosis.

However, in these series of patients, the difficulties in diagnosis were not the main cause of discussion, mean age at the time of suspicion was early (18 months old). These results might be explained by a bias in the selection of patients.

In spite of the limitations related to the size of the sample, the type of design, the absence of a control group, and a direct measure of the impact in care practices, the results of the self-perception survey about changes in skills and competences showed the importance of the ECHO model in training. Most surveyed subjects did not have previous training on this topic. Therefore, this situation could explain the high perception of both the lack of skills and competences for diagnosis as well as therapeutic approach at the beginning of the teleECHO clinics. This is one of the main obstacles at the primary care level. And as it was previously informed by Mazurek et al, Project ECHO is a strategy to improve the self-perception about changes in skills and competences in all explored dimensions to reduce health inequalities and advance access to evidence-based knowledge around the world.[19,22]

Conclusions

The ASD experience is the first ECHO project implemented in pediatrics in Uruguay. The results of this experience have shown that ECHO may have an important role to improve access to diagnosis and treatment of children with other complex conditions. A community of practice was achieved through participation in the ECHO Autism clinics, and self-perception about skills and competences in diagnosis and treatment of children with autism has improved.

Future studies with an experimental design using the ECHO model for training are necessary to assess the impact on clinical practices and patient outcomes.

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Author Contributions

GG: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

ALC: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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JF: Contributed to conception; contributed to analysis and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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Declaration of Conflicting Interests

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