

Expanding a Regional Sickle Cell Disease Project ECHO[®] to Rapidly Disseminate COVID-19 Education

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Purpose: Healthcare providers faced numerous knowledge gaps and challenges with adapting practice behaviors in light of the COVID-19 pandemic. In response, an established virtual sickle cell disease (SCD) telementoring program rapidly expanded from monthly evidence-based didactic sessions focused on medical and psychosocial complications of sickle cell disease, to additional supplemental COVID-19 sessions with emerging pandemic topics and forums for shared experiences to address this timely educational need among multidisciplinary healthcare providers.

Methods: In March 2020, the COVID-19 and Sickle Cell Disease Project ECHO[®] telementoring series was launched with a rapidly evolving curriculum of contemporary topics and case presentations. Topics included COVID-19 specific management for children and adults with sickle cell disease and strategies to adapt care and communication during the pandemic. Participants completed evaluations after each session.

Results: From March 2020 to February 2022, there were 20 COVID-19 and SCD Project ECHO[®] sessions held with an average of 43 participants per session, which is over a 170% increase from the average SCD ECHO monthly attendance pre-pandemic. Participants represented 21 states and 3 countries. A majority of participants (91%) self-reported significantly improved knowledge of COVID-19.

Conclusion: Project ECHO[®] is a successful educational strategy to diffuse knowledge using a virtual platform during a public health emergency, by facilitating shared learning among a community of practice that specializes in the management of sickle cell disease.

Keywords: sickle cell disease, COVID-19, telementoring, project ECHO[®], continuing education

Introduction

Sickle cell disease (SCD), the most common genetic disorder in the United States, is a group of blood disorders affecting nearly 100,000 Americans.¹ Typically diagnosed at birth with newborn screening, SCD can cause a myriad of acute and chronic clinical complications throughout the lifespan, leading to poor health-related quality of life and early mortality.² In the United States, SCD is most commonly found among African-Americans and Hispanics, and these patients face numerous health disparities and inequities across the healthcare system, and many also face additional socioeconomic challenges.³

Early in the pandemic, the Centers for Disease Control and Prevention (CDC) identified SCD as an underlying, pre-existing medical condition with a suggestive higher risk of severe illness from COVID-19.⁴ Moreover, a registry study designed to track complications and outcomes of children and adults with SCD and COVID-19 found higher rates of hospitalization, intensive care unit admissions and even death⁵ among this vulnerable patient population.

The pandemic presented a need for “just-in time” virtual education for healthcare provider teams to improve knowledge of the prevention, diagnosis and treatment of COVID-19, along with the medical and psychosocial impact

on individuals with SCD, and shared learning about rapid practice changes, such as an immediate shift to telemedicine for care delivery.

Project ECHO[®] (Extension for Community Healthcare Outcomes) is a virtual, web-based telementoring model that shares best practices and allows diffusion of knowledge through evidence-based curriculums and de-identified case-based presentations. The sessions are an hour in duration and typically consist of a 20–25 minute didactic evidence-based presentation, followed by a de-identified patient case to elicit medical and psychosocial feedback and recommendations about treatment course from subject matter experts.⁶

Sickle Treatment and Outcome Research in the Midwest (STORM), an eight-state Health Resources and Services Administration (HRSA) funded Sickle Cell Disease Treatment Demonstration Project, is a regional provider network for pediatric and adult providers. STORM has successfully utilized the Project ECHO[®] model since 2016 as a monthly hour-long educational strategy to increase the numbers of healthcare providers knowledgeable about best practice evidence-based management of pediatric and adult SCD.⁷ In rapid response to the COVID-19 pandemic, the STORM regional coordinating center team that serves as the STORM Project ECHO[®] hub, leveraged this existing telementoring framework to launch a series of SCD and COVID-19 focused sessions within days of the public health emergency declaration.

Methods

In March 2020, two introductory COVID-19 and SCD ECHO sessions were held as shared learning opportunities for healthcare providers to discuss the impact of abrupt widespread quarantines and shelter-in-place orders on clinical practice as well as their patients and to discuss the immediate medical and psychosocial impacts of COVID-19 on patients with SCD (ie housing, food security, transportation, childcare, homeschooling, etc.). COVID-19 and SCD ECHO sessions were open to any interested healthcare provider. Advertisements for the COVID-19 and SCD ECHO sessions were widely disseminated to those providers who had previously attended a STORM ECHO session. Virtual sessions were held using web-based Zoom[®], lasted one-hour in duration, and included a didactic presentation and de-identified case presentations about children or adults with SCD diagnosed with COVID-19. The series began with weekly frequency and later tapered down to monthly, and then “as-needed” to coincide with significant developments in the pandemic (ie new variants, surges and high positivity rates, vaccine approval, etc.) that could impact the care of individuals with SCD.

The evolving learning curriculum included didactic presentations such as: telemedicine best practices; patient and provider SCD specific advisories from the Sickle Cell Disease Association of America; a newly-developed SCD COVID-19 surveillance registry; blood safety and transfusion practices; serology for SARS-COV-2; school intervention approaches to address online learning barriers; multi-system inflammatory syndrome in children (MIS-C); mental health and coping; effective vaccine messaging and communication with patients; an overview of vaccine development; contemporary updates to new variants (ie Delta and Omicron); and emerging COVID-19 treatments (Table 1). Participants were offered Continuing Medical Education; nursing continuing education credits; and American Board of Pediatrics and American Board of Internal Medicine Maintenance of Certification (Part 2) credits. IRB approval was obtained from Cincinnati Children’s Hospital Medical Center.

Results

From March 2020 – February 2022, there were 20 COVID-19 and SCD sessions held (in addition to regularly scheduled SCD ECHO sessions) that averaged 43 multi-disciplinary providers per session, which is an over 170% increase from the average SCD ECHO pre-pandemic monthly attendance (Figure 1). COVID-19 and SCD ECHO attendees represented pediatric and adult providers from primary care and hematology practices (academic and community), as well as public health practitioners from 21 states, Canada, Kenya and Nigeria. The majority of participants were physicians (39%), registered nurses (13%), nurse practitioners (8%) and other disciplines including clinical research coordinators, social workers, community health workers, school intervention specialists, psychologists, newborn screening coordinators, public health officials, pharmacists and medical trainees. Over 91% of participants reported that the sessions significantly improved their evidence-based knowledge of COVID-19.

Table I STORM TeleECHO COVID-19 and Sickle Cell Disease Didactic Schedule

Date	Topic
March 19, 2020	COVID-19 Open Forum
March 26, 2020	COVID-19 Open Forum
April 2, 2020	Telemedicine Best Practices
April 2, 2020	Sickle Cell Disease Association of America – Medical and Research Advisory Committee Patient and Provider Advisories
April 9, 2020	Sickle Cell Disease COVID-19 Surveillance Registry
April 23, 2020	Blood Safety and Transfusion Practices
April 30, 2020	Serology for SARS-CoV-2
May 7, 2020	Lessons from the Field – Telemedicine
May 28, 2020	Mental Health and Coping During COVID-19
June 4, 2020	COVID-19-Associated Multisystem Inflammatory Syndrome in Children (MIS-C)
June 11, 2020	Are Children Immune to COVID-19?
July 30, 2020	Back to School Planning for Students with SCD
August 27, 2020	An Update on COVID 19 and SCD Patient Outcomes
January 21, 2021	Sickle Cell Disease Association of America – Medical and Research Advisory Committee Recommendation for COVID Vaccination
March 18, 2021	COVID-19 Vaccine Update
April 15, 2021	COVID-19 Vaccine Communication
September 30, 2021	The Evolving COVID-19 Pandemic: Delta and its Effects on our Pediatric Population
October 14, 2021	Monoclonal Antibody (mAbs) Treatment Guidelines for Patients with SCD and COVID-19
January 6, 2022	Update on COVID-19 Therapies: Pediatric Indications
February 24, 2022	Mental Health of Children with SCD: What are the Pandemic's Effects?

Qualitative session evaluation comments highlighted several changes in practice as a result of the COVID-19 ECHO, such as “I am going to share the information about depression rates and food insecurity with my team to see how we can be of assistance to the families we work with”, as well as confidence with referring patients with SCD who test positive for COVID-19 for monoclonal antibody therapy; and increased confidence with “the ability to gain trust and achieve shared decisions with patients when discussing COVID-19 vaccinations by using new communication strategies”. Participants reported real-time dissemination of late-breaking information, such as efficacy of COVID vaccines or how multi-inflammatory syndrome in children (MIS-C) was affecting children with SCD, and the latest research data were highly beneficial during an evolving public health situation.

Discussion

Project ECHO[®] can be a highly effective, low-cost, and innovative approach to virtually deliver time-sensitive medical education and best practices while fostering shared learning within a community of practice during a global pandemic. Because of the unprecedented gaps in knowledge about COVID-19, including emerging public health recommendations about best practices such as masking, social distancing, and quarantine recommendations, as well as testing and

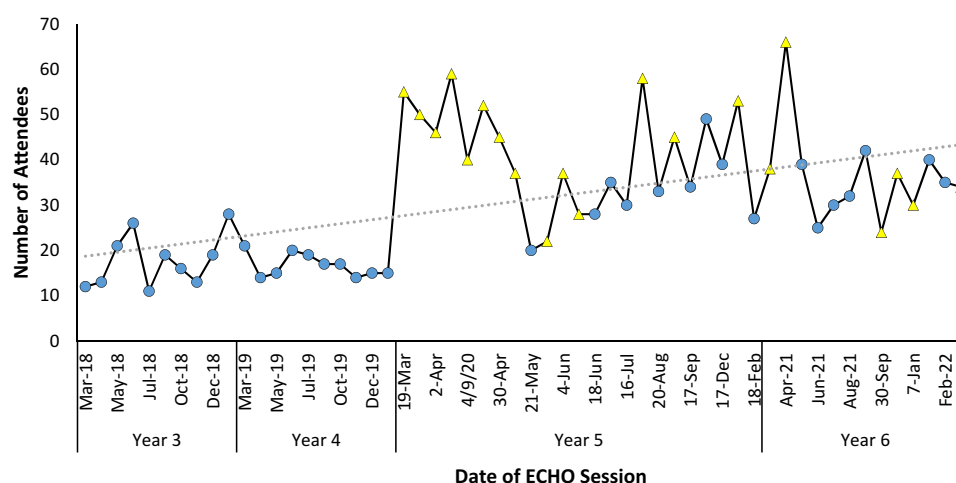


Figure I STORM TeleECHO attendance.

Notes: ● Regular ECHO. ▲ COVID-19 ECHO.

eventually vaccination, all of which rapidly impacted care delivery in this community of practice was critical for the dissemination of knowledge and to facilitate group discussions among multidisciplinary healthcare providers.

The continued increase in the number of COVID-19 and SCD ECHO participants that was sustained throughout the series has demonstrated a continued need for this specific educational forum that provided an opportunity for providers to share practice changes, new clinical protocols, patient education and other contemporary resources among multidisciplinary teams during an unprecedented time when in-person continuing medical education was not feasible, and when information was frequently changing and needed to be disseminated rapidly.

Moreover, because SCD is a rare disorder that affects predominantly minority populations, STORM's COVID-19 and SCD ECHO provided an opportunity to engage community providers and academic medical centers, regardless of geographic location, to discuss the specific emerging and immediate needs of this underserved population (ie housing, homeschooling, food security, transportation, internet access, etc.). As the pandemic progressed, the COVID-19 and SCD ECHO became useful during the vaccine rollout phase to address the importance and safety of the vaccine, as well as strategies to address vaccine hesitancy with this vulnerable, at-risk population.

These targeted COVID-19 and SCD educational sessions will continue as long as there are emerging developments in the pandemic as an educational platform for multidisciplinary providers to present current research and discuss the long-term impact of COVID-19 on clinical practice, as well as medical and psychosocial outcomes for children and adults with SCD.

Disclosure

The authors report no conflicts of interest in this work.

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