

Collaborating to Advocate in Primary Care for Children During COVID-19

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The St Louis Regional Pediatric Learning Collaborative of pediatric primary care providers and infectious diseases specialists formed in March 2020 to address the needs of children and families during the coronavirus disease 2019 (COVID-19) pandemic. More than 400 pediatric primary care providers participated, using a listserv to discuss care and organize webinars to provide updates on local and national data and plan next steps. To inform local decision-making about care and testing for severe acute respiratory syndrome coronavirus 2, 95 providers from 26 practices partnered with the local practice-based research network to rapidly collect and share data about children with COVID-19–like symptoms. Of 2162 children tested for severe acute respiratory syndrome coronavirus 2, 9% had positive test results. Test result positivity was 33% if a patient was exposed to a confirmed case of COVID-19 and 4% if they had COVID-19–like symptoms and no exposure. School or day care attendance was associated with lower rates of positive test results. Although not originally planned, these findings drove local advocacy efforts by the Collaborative for increased access to testing and contact tracing and safe in-person school. Members communicated directly and collectively with local politicians, provided advice and resources for school boards and superintendent groups, and appeared on various media platforms. In these efforts, they shared local data, highlighting the lower rate of positive test results for children in school to support the idea that schools could be safely open. Outreach from trusted pediatricians sharing prospective, timely, local data sustained in-person school for some districts and aided in future in-person openings for other school districts.

Sometimes advocacy evolves quickly in response to urgent need. We report on the opportunity for advocacy work realized during our efforts to provide optimal care for children during the coronavirus disease 2019 (COVID-19) pandemic. Early in the pandemic, pediatric primary care providers (PCPs) faced unprecedented challenges in caring for their patients. Given a lack of information about COVID-19 in children, PCPs in our community were motivated to work together to optimize care. To this end, they formed the St Louis Regional

Pediatric Learning Collaborative (the Collaborative) with local pediatric infectious diseases experts. The Collaborative was operationalized through our long-standing practice-based research network (PBRN) and a newly implemented listserv. Frequent webinars were held to share local, national, and international information about COVID-19, discuss concerns and experiences, and plan action steps.

Initially, providers used the listserv to ask questions about patient management, such as the accuracy

abstract



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Drs Harrison, Garbutt, Newland, and Plax conceptualized and operationalized the Collaborative and designed the data collection instruments, drafted the initial manuscript, and reviewed and revised the manuscript; Dr Sterkel conceptualized and operationalized the Collaborative, designed the data collection instruments, and reviewed and revised the manuscript; Ms Dodd conceptualized and operationalized the Collaborative and designed the data collection instruments, collected data, coordinated and supervised data collection, and reviewed and revised the manuscript; Ms Wang designed the database, conducted the initial analyses, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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and availability of testing for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), access to and appropriate use of personal protective equipment (PPE), and recommendations for quarantine. An early concern was an inability to distinguish COVID-19 from other common childhood infections especially in light of limited testing availability. These limitations included few test sites for pediatric patients, long delays in receiving test results, uncertainty about the accuracy of test results, and the lack of in-office testing due to shortages of protective equipment and test supplies. The challenges of accurate, timely diagnosis limited optimal patient care, resulted in unnecessary quarantine recommendations and created significant family hardship. The Collaborative recognized that testing and quarantine decisions had critical effects on family functioning specifically regarding the impact on safe school and day care attendance.

To address these concerns, the Collaborative circulated a list of area pediatric testing sites and collectively developed a clinical testing algorithm on the basis of Centers of Disease Control and Prevention recommendations at the time.¹ The algorithm considered exposure to a known COVID-19 case and presenting symptoms to inform testing decisions and recommendations for return to school or day care. To understand presentations of COVID-19 in children in our community and determine the utility of the developed testing algorithm, members of the Collaborative worked with the PBRN to implement a mechanism to rapidly gather and share information about COVID-19 in symptomatic children across their outpatient offices. Although many studies have revealed that children with COVID-19 typically have mild viral

symptoms and rarely are severely or critically ill,²⁻⁹ local data from a cohort of children with symptoms suggestive of COVID-19 provided opportunity to identify discriminating factors for COVID-19 to guide testing decisions.

To this end, between June 1, 2020, and October 16, 2020, 95 PCPs prospectively reported data for 2162 patients who presented with symptoms suggestive of COVID-19 and were tested for SARS-CoV-2 (84% white, 6% African American or Black, 3% multiracial, 2% other, 5% unknown; 4% Hispanic; 15% government insurance). Nine percent had positive test results. The majority of these patients had a history of significant contact with a confirmed case of COVID-19 (59%) and had COVID-19–like symptoms (89%). The median number of symptoms at presentation was 3 (range 1 to 10). For many symptoms, although statistically significant in this large sample, the difference in frequency between children with and without COVID-19 did not vary in a clinically significant way. For example, the most common symptom of runny nose or congestion was present in 66% of patients with COVID-19 and in 73% without COVID-19. Similarly, cough was present in 48% with COVID-19 and 57% without. Using these local data, we learned that the clinical algorithm could not reliably identify those with and without COVID-19. In effect, COVID-19 cannot be ruled out clinically in most cases for children with viral symptoms, and, therefore, widespread access to reliable testing for SARS-CoV-2 was needed for optimal patient management.

We also collected information about school and day care attendance. Among the 1403 patient forms that provided specific information about school attendance, 767 (55%) children attended school and 636

(45%) did not. Test result positivity rate for SARS-CoV-2 virus was 6% for the group attending school and 12% for the group not in school, $P < .001$, relative risk: 0.49 (95% confidence interval: 0.34 to 0.71). Similarly, for the 883 forms that provided information about attendance at a day care center, 267 (30%) attended and 616 (70%) did not. The values for test result positivity for the 2 groups were 3% and 11%, respectively, ($P < .001$, relative risk: 0.28 [95% confidence interval: 0.13 to 0.57]).

As we collected and analyzed our data, there began to be more focus locally and nationally on the potential educational, health (including mental health), and economic consequences of prolonged school closures for children, especially for children of color and those from a lower socioeconomic status.¹⁰⁻¹⁶ We realized our unique opportunity as a Collaborative to collectively use our local data to advocate widely and often for children and their families.¹⁷ Although disadvantaged children were underrepresented in our local data collection, our advocacy efforts intentionally included school districts serving diverse populations. The goals of these advocacy activities were to increase access to testing, provide optimal care for children, and to support safe day care and in-person school attendance for all children in our community.

METHODS AND PROCESS

Over ~4 months, 95 PCPs from 26 practices spanning the greater St Louis area participated in data collection, sharing data on >2000 children presenting with COVID-19–like symptoms. In the absence of a common electronic health record, the data were collected prospectively by using a 1-page form. This rapid data

collection was possible because of the infrastructure of the established PBRN, which provided expertise in data collection, data entry and, when necessary, obtained data sharing agreements. Additionally, because the project was to improve care locally, it was determined not to be human subjects research by the Washington University Human Research Protection Office.

Findings from the data collection drove advocacy efforts by members of the Collaborative. In addition to sharing local data within the group, advocacy work included providing advice and resources for school boards and superintendent groups, appearing on various media platforms and communicating directly with local politicians via letters developed collectively and signed by many Collaborative participants.

Several factors were critical to the success of these advocacy activities. The urgency and commitment of the providers to support the health and wellbeing of their patients and patient families was essential. The Collaborative ensured that providers banded together to receive group support and advocated in concert together. In addition, infectious diseases specialists provided the most up-to-date knowledge and expert opinion, shared local and national data as they became available, and participated in the advocacy work. These specialists worked diligently to address providers' concerns in real time via the listserv and through webinars. The uncertainty of the times meant prompt dissemination of shared new knowledge was critical for participating pediatric care providers, and this was a strong motivator for participation and ongoing engagement in both pediatric care and advocacy.

The infrastructure provided by the PBRN was also important. Relationships among local pediatric care providers and the PBRN were long-standing and tested. The PBRN has existed for almost 20 years and was trusted by the community of pediatric care providers to deliver help and support. This partnership facilitated prospective data collection and storage of published articles, reports and other resources that were relevant for providing optimal care, advice, and advocacy (<http://wupaarc.wustl.edu/>). The Collaborative served as a platform to organize members in rapid deployment advocacy activities. Letters to local politicians were developed collectively via the listserv, and resources for school boards were shared via the PBRN Web site. Importantly, many members of the Collaborative already had relationships with local politicians and other key decision-makers from past advocacy efforts. These long-standing trusted relationships between elected leaders and pediatricians provided greater access for discussion about pediatricians' concerns and sharing of local data.

OUTCOMES

Advocacy to increase access to SARS-CoV-2 testing through the local hospital system was unsuccessful for many months. However, PCPs increasingly provided in-office specimen collection for testing at private laboratories, supporting each other with information about local laboratory resources, PPE purchasing, and advice about operationalizing telemedicine and parking lot visits. This alternative strategy rapidly increased pediatric access to testing in the community.

Regarding advocacy work to promote safe in-person school and day care attendance, 3 activities seemed especially impactful: (1) a

letter in late July, signed by >70 pediatric providers and sent to 2 St Louis Congressional Representatives; the letter advocated for more rapid use of the Coronavirus Aid, Relief and Economic Security Act funds to expand SARS-CoV-2 testing and contact tracing; because some of our Collaborative members had long-standing relationships with elected officials, the letter was followed by a phone conversation on next steps; our members of Congress then worked with local political officials to improve partnership and communicated back directly to the Collaborative; (2) a letter sent in August to the Saint Louis County Executive advocated for in-person school; the letter was signed by close to 100 pediatric practitioners and addressed school mitigation strategies of masking, social distancing, and PPE and cleaning supplies for schools. In addition, the letter called for limiting large gatherings and closing facilities associated with disease spread (bars, indoor gathering sites) while maintaining in-person school. Pediatricians reinforced the letter with media work on television and radio; this led to dialogue with the county executive and greater pediatric representation in workgroups that included school superintendents and the metro-wide COVID-19 task force; (3) in early November, we developed a one-page document outlining the results of the Collaborative data gathering project; the document was presented to local public health officials, political leaders, and school officials in various meetings; it highlighted the lower rate of positive test results for children in school and day care, supporting the idea that local daycares and schools could be open safely; this one-page document sustained in-person school for some districts and aided in future in-person openings for

other school districts; pediatricians reinforced these results through continued engagement with local school boards, private schools, and superintendent group meetings.

LESSONS LEARNED

Our experience revealed that important and successful advocacy work by community pediatricians can occur through a timely response to urgent needs. The goal of our project was to provide optimal care and improve access to in-person school and day care for local children during the COVID-19 pandemic. It involved organizing pediatric care providers to follow best practices that were constantly changing, standardizing testing recommendations during a confusing time when consensus for pediatric patients was lacking, and collecting data to inform future decision-making for schools and daycares. Although not originally planned, all of these activities provided opportunities for local PCPs to use their shared knowledge to advocate widely in our community for improved outcomes and opportunities for children. This advocacy supported local school leaders and public health officials to help most local schools open.

Our project revealed that pragmatic collaboration between community-based PCPs, academically affiliated pediatric infectious diseases experts, and a PBRN led by academicians could effectively organize advocacy efforts during the COVID-19 pandemic. National organizations like the American Academy of Pediatrics and the American Medical Association have provided structure and resources to support physicians in caring for patients during the pandemic.^{18,19} The American Academy of Pediatrics has advocated at the federal and state level for financial relief for patients and providers, access to testing, and

increased resources for schools, and it has encouraged pediatricians to engage in advocacy efforts such as signing letters to state and federal politicians. However, in many communities, decisions about school opening during the COVID-19 pandemic are being made at the community level and have been influenced by both local positivity rate and transmission dynamics as well as local politics, including school boards. Our advocacy work in this area was community based and rooted in what pediatricians were seeing “on the ground” as the pandemic unfolded, and it was supported by local data that aligned with the growing body of literature in the United States about the safety of in-person school.²⁰⁻²³ The need for advocacy was clear to providers, and, therefore, strategies were quickly developed, shared through listserv discussions, webinars, and other means and then rapidly deployed for action. Many members of the Collaborative already had ongoing relationships with local politicians and school boards from previous involvement, so these were leveraged to increase pediatrician influence on groups making decisions at the local level. Both newly forged and ongoing relationships were critical to the success of the advocacy activities reported here.

The Collaborative listserv is now cemented in our community as a collegial network that offers an effective platform for timely problem solving and support. As of June 14, 2021, the total number of participants on the listserv is 447. Providers continue to answer questions and share information, and experts are consulted for advice. For example, in response to recent questions and discussion about care for pandemic-related mental health issues for children and teenagers, Dr Katie Plax, an expert in adolescent

medicine and a listserv participant, provided 2 webinars covering care of patients with anxiety and suicide risk assessment, each attended by >50 PCPs. These timely webinars were especially relevant because recent data reveal that emergency department visits for suspected suicide attempts among children aged 12 to 17 years has dramatically increased during the pandemic.²⁴ Our PBRN has disseminated resources and tools to support primary care management of depression and anxiety through the listserv and is conducting interviews with providers to describe their experiences in providing mental health care during the pandemic. We will use this next round of local data to advocate for needed services for children in our community.

CONCLUSIONS

While working together to provide optimal care for families in the face of great uncertainty, our Collaborative accomplished many advocacy goals focused on the needs of children and families during the COVID-19 pandemic. We conclude that timely advocacy efforts can be effective when pediatric providers, both community and academically based, band together with shared goals. In our case, the Collaborative was able to rapidly gather local data about COVID-19 in children and influence school reopening decision using letters, media, and relationships built with local leaders.

Current efforts of the Collaborative are focused on the continuing challenges for primary care providers presented by COVID-19, specifically the increased demand for mental health care associated with the pandemic. This work presents an opportunity to advocate for a coordinated system of mental health care in our community to

optimize outcomes and use of resources. As children's hospitals continue to sound the alarm of the behavioral health crisis and difficulties in caring for these children, efforts among primary care clinicians to fill the increasing gap in mental health care services for children is ever more critical.

Although clinicians who care for children from disproportionately impacted racial groups participate in the listserv, few of these clinicians participated in the data collection project, resulting in underrepresentation of these children in our sample. A goal of the Collaborative is to engage more primary care clinicians who provide care to populations of racially diverse children and children living in poverty to extend the reach of this work and expand opportunities for local advocacy.

The unique challenges faced during the pandemic drove the development of our Collaborative, which will certainly continue to shape primary pediatric care in our community moving forward. It is a clear demonstration that collaboration among academic and community pediatricians is essential to ensure the best care for our children and families. Our model has great potential for effectively addressing future new or rapidly evolving pediatric health crises here and in other communities.

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ABBREVIATIONS

COVID-19: coronavirus disease 2019
PBRN: practice-based research network
PCP: pediatric primary care provider
PPE: personal protective equipment
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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