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Pediatric health care use during the COVID-19 pandemic: Lessons learned from the initial 2020 wave

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Abstract

Objective: During the height of the coronavirus disease-2019 (COVID-19) pandemic, there was a decline and shift in pediatric medical care use. We aimed to assess changes to pediatric medical use and perceptions/barriers that influenced caregivers' decision-making during the New York State mandated lockdown from March 22 to June 8, 2020, in a population that opted to use the pediatric emergency department (PED) during this period. This study was conducted in New York City (NYC), one of the epicenters at the height of the COVID-19 pandemic.

Methods: From June 14 to December 28, 2020, a convenience sample of caregivers who brought children 0–17 years to a NYC PED completed a survey.

Results: Participants in the survey included 290 caregivers: 76% were Hispanic; 91% reported having accessed medical care when their children were ill during the lockdown. In-person primary care visits decreased from 64% before to 9% during lockdown; 28% missed well-child checkups or vaccinations, and 26% missed specialist appointments. Telemedicine usage increased from 10% to 54%; none reported lack of internet or electronic devices as barriers to using telemedicine. Regarding access to care: 36% perceived increased difficulty during the lockdown, whereas 56% felt no difference. Barriers included fear of contracting COVID-19 and government advice to avoid health care visits for minor problems.

Conclusion: During the initial wave of the COVID-19 pandemic, medical care shifted from an in-person to a virtual platform. Identification of factors and barriers surround-ing caregivers' decision-making may positively inform strategies toward future public health emergencies.

KEYWORDS

caregivers, COVID-19, health care use, pandemic, pediatric emergency department

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1 | INTRODUCTION

1.1 | Background

Since March 2020, the United States has seen over 87 million cases and more than 1 million deaths due to COVID-19.¹ Current data from the American Academy of Pediatrics show that children accounted for approximately 19% of the total cumulative cases since the onset of the pandemic.² Although hospital inpatient units and emergency departments (EDs) were overwhelmed with critically ill adult patients, both pediatric emergency department (PED) visits and hospitalizations dropped worldwide during the initial wave of the pandemic.^{3–5} This steep decline also occurred in our academic medical center, which is located in New York City (NYC), one of the epicenters during the first wave of the COVID-19 pandemic in the spring of 2020. The reasons for this substantial decline in PED visits and hospitalizations are not well understood.^{6,7} Gaining these insights from the caregivers who chose to visit the ED during the lockdown could help toward the development of necessary infrastructures to ensure equitable access to care and to improve the accurate dissemination of medical information and education in preparing for future surges and other public health emergencies.

1.2 | Importance

Our study prospectively assessed caregiver perceptions of health care options during the lockdown period and barriers to accessing medical care in a US population. Two previous prospective studies of caregivers in Ireland and England^{8,9} have reported on the effect of COVID with regard to caregivers' medical care use for their children. However, their study populations are very different from ours. Although there are published studies from the United States,⁵ these are retrospective and derived from abstraction of electronic data. This type of information can provide only a limited understanding of caregivers' perceptions and factors that influenced their decision-making on the use of health care for their children during the COVID-19 pandemic.

1.3 | Objectives

Our study aims were to assess the following during the New York State mandated lockdown period from March 22 to June 8, 2020, during the height of the COVID-19 pandemic: patterns of pediatric health care use by an urban PED patient population; factors that influenced caregivers' decision-making to access health care for their children; caregivers' perceptions on ease of accessing medical care, and their inputs to overcome barriers and prepare for future health care emergencies.

The Bottom Line

In this survey study based in a pediatric emergency department among primarily Latino residents of New York City during the COVID-19 pandemic, parents commonly reported missed visits for routine care and also reported a substantial shift to virtual visits.

2 | METHODS

2.1 Survey development

The survey was developed by the primary authors in consultation with research faculty members in our department and expert input from the Center for Education Research and Evaluation at Columbia University.

After multiple iterations the survey was trialed among 10 faculty members and nurses for specific feedback on the following: its understandability, the order of questions, answer options provided, ease of answering the questions, and length of the survey. After their input was incorporated, we piloted the survey on 5 caregivers and incorporated their feedback as well.

The survey was available in English and Spanish, which was translated by an institutional review board (IRB) Spanish-certified staff member.

2.2 Study design

We surveyed a convenience sample of caregivers who brought their children to a PED located in NYC between June 14 and December 28, 2020. This study was conducted immediately after the lifting of the New York State stay-at-home mandated lockdown period from March 22 to June 8, 2020, during which all research at our institution was suspended.

Caregivers were eligible if they were the legal guardians of children from 0 to 17 years and spoke English or Spanish. Caregivers were recruited during their PED visit by research associates, nurses, and physicians. After consenting to participate, caregivers were given a QR code or internet URL to access an online survey that could be completed electronically on any smartphone, computer, or tablet either during their time in the PED or after discharge. No identifying protected health information was collected. We explicitly asked caregivers if they had completed a survey before and excluded them if they had.

The study was approved by the Columbia University IRB.

2.3 Study setting and population

The study was conducted at an inner-city urban PED within an academic children's hospital in NYC with an average annual census of 50,000 patients ranging in age from 0 to 19 years, with approximately 67% Hispanic.

2.4 Study variables and measures

Demographics of caregivers and their children's insurance information were collected. To assess changes in acute pediatric medical care use, we collected the modalities of medical care that caregivers used for their child's illness during the lockdown and compared this to before the COVID pandemic.

For factors that may have influenced caregivers' decision-making on acute modalities of medical care for their children, we sought to see if the illness symptoms may have changed or affected the caregivers' decision. We collected the illness symptoms experienced by their children during the lockdown and compared them to the symptoms that brought them to this PED visit after the lifting of the lockdown during which this study was conducted. We also asked why caregivers chose to use the PED for this sick visit versus other options.

To better understand reasons why caregivers chose not to seek medical care for their child's illnesses during the lockdown, we asked them to select from the following options and/or enter free text comments: following media and government advice to not seek care for minor problems; their child's illness was not serious enough; worried about contracting or transmitting COVID at a medical facility; their child's primary care physician (PCP) office was closed or unavailable; inability to use telemedicine services because of lack of electronic devices or internet access or because of the cost of the visit and lack of insurance; and fear of using public transportation.

To ascertain the impact of the lockdown on non-urgent medical care, caregivers were asked about any missed routine well-child visits, specialist visits or tests, difficulty filling prescriptions, and whether they were able to maintain follow-up care for chronic medical issues. They were able to provide free text responses if they were affected.

For caregivers' perceptions around medical access, we asked if they felt access was more difficult during the lockdown and solicited their ideas on what would be helpful in caring for their children should there be another pandemic in the future.

While data collection was still in progress, we noted an increase in the use of telemedicine. Additional questions were added to our survey on October 27, 2020, to better characterize this phenomenon. Results from questions on telemedicine were analyzed separately.

2.5 | Data analysis

Data was collected using Qualtrics, a Health Insurance Portability and Accountability Act certified survey tool provided by our institution. Data were anonymized and analysis was performed through Qualtrics JACEP OPEN

TABLE 1 Demographic characteristics of caregivers and children's insurance

Caregiver	Percentage (%)			
Age (N = 243)				
<20 years	6.2			
21–40 years	69.5			
41–60 years	24.3			
Race (N = 240)				
American Indian or Alaskan Native	4.6			
Asian	2.5			
Black or African American	19.2			
Native Hawaiian or Pacific Island	1.2			
White/Caucasian	20			
Other (all Hispanic/Latino)	30			
Prefer not to answer	20			
Unknown	2.5			
Ethnicity ($N = 238$)				
Hispanic or Latino	76.5			
Non-Hispanic or Latino	18.1			
Prefer not to answer	4.6			
Unknown	0.8			
Highest school education ($N = 234$)				
Grade school	8.1			
High school	29.9			
Technical school	7.3			
College	36.8			
Graduate school	17.9			
Child's insurance ($N = 235$)				
Government insurance/Medicaid	61.0			
Private insurance	32.4			
Other	6.2			
None	0.4			

and Excel. Results were reported as percentages of total responses. For many questions, participants could choose more than 1 answer. Consequently, data for some variables totaled more than 100%.

3 | RESULTS

Two hundred and ninety participants completed the survey.

3.1 | Characteristics of study subjects

The demographics of the participating caregivers and their children's medical insurance coverages are summarized in Table 1. Among those who responded, 76% were Hispanic and 62% had above high school education. Almost 96% of caregivers identified having a primary



 TABLE 2
 Access to acute medical care before and during lockdown

Modalities of medical access	Before lockdown (N = 268) (%) ^a	During lockdown (N = 74) (%) ^a
In-person PCP	64	9
PED	32	45
Urgent care	20	14
Electronic communication with PCP/specialist	31	31
Telehealth	10	54

^aPercentages are calculated as the number who selected the specific modality of medical care divided by N = the number of total acute illness during the specified time period. Abbreviations: PCP, primary care physician; PED, pediatric emergency department.

care physician (PCP) for their children and 96% of the children had insurance coverage.

3.2 | Access to acute medical care before and during lockdown

Caregivers obtained medical care for their sick or injured children in 91% of illness episodes during lockdown. Types of acute medical care accessed before and during lockdown are presented in Table 2. Patterns of acute medical care access during lockdown shifted away from in-person visits. There was a steep decline in PCP office visits and a dramatic increase in telehealth during the lockdown as compared to before the lockdown.

3.3 During the lockdown period: Acute illness symptoms

Twenty-four percent of caregivers reported that 1 or more of their children were sick or injured during the lockdown for a total of 74 illness episodes. These children's symptoms are summarized in column 1 of Table 3. The mean age of these children was 7 years with a range from 7 months to 17 years.

3.4 | Why some chose not to seek care during lockdown

Among the caregivers whose children were sick during the lockdown, some decided to not seek medical care. Their reasons included the following: concern that they or their children would catch COVID (43%), adhering to media and government advice not to go to doctors for minor problems (43%), their children's illness not being serious enough to warrant accessing medical care (29%), fear of using public transportation (14%), or closure of their child's primary care office (14%).

TABLE 3 Children's presenting symptoms during PED visit after lockdown at time of survey and symptoms during lockdown

Acute symptoms	During lockdown (N = 74) (%) ^a	Current PED visit (N = 285) (%)ª
Fever	44.6	25.9
URI	43.2	12.3
Difficulty breathing	27.0	12.9
Ear pain	10.8	2.5
Gastrointestinal	24.3	23.5
Headache	22.9	6.3
Rash	12.1	5.6
Lacerations	0.0	4.6
Sprains/fractures	8.1	9.5
Chronic medical problem	9.5	4.2
Other ^b	18.9	22.8

Abbreviations: PED, pediatric emergency department; URI, upper respiratory infection.

^aPercentages are calculated as the number who checked the specific symptom divided by the number who reported having acute illness during the specified time period.

^bIncludes seizures, non-musculoskeletal pain and urological symptoms.

3.5 | Post lockdown PED visit at time of study enrollment: Acute presenting symptoms

The children's symptoms that prompted caregivers to seek medical care for the current PED visit are summarized in column 2 of Table 3. Fever was the most commonly reported complaint. Because caregivers could check more than 1 symptom for their children's PED presentation, the sum of the percentages exceeded 100%. Reasons caregivers gave for choosing to use the PED rather than other medical facilities for the current illness included the seriousness of their child's symptoms (28.4%), promptness of evaluation in the PED (14.0%), quality of PED service (14.0%), their doctor's referral (11.4%), familiarity with the PED from prior visits (10.3%), availability of specific services (9.2%), and proximity to their home (4.4%).

3.6 | Access to routine and chronic non-urgent medical care during lockdown

For routine health care, 28% of caregivers reported missing their children's well-child checkups or vaccinations during lockdown. Commonly cited reasons were closure of PCP offices (26%), cancelations or lack of available appointments with PCP (13%), and fear of exposure to COVID (12%). Furthermore 26% reported missing scheduled medical tests or specialist appointments, of which the majority (59%) were because of delayed, canceled, or unavailable appointments and clinic closures. Most caregivers did not report any difficulties in filling prescriptions. Among those who did, the main reasons were closure of pharmacies and medications being out of stock.

Fifty-seven percent of children who had chronic conditions required medical attention during the lockdown period. Care was obtained via telephone with specialists (29%), telemedicine visits with specialists (42%), and in-person visits with PCP (29%), PED (29%), or urgent care (9%). Only 6.5% reported in-person office visits with specialists.

3.7 | Telemedicine usage before and during lockdown

Of the 92 caregivers who completed the questions regarding telemedicine, which were added later during the study period, 37% had heard of telemedicine before the pandemic and 7% had used telemedicine. Before the lockdown, reasons cited for not using telemedicine when medical care was needed included the unavailability of telemedicine (44%), caregivers' not knowing how to use telemedicine (17%), and insurance not covering the cost of telemedicine services (6%).

During the lockdown, 54% of caregivers with sick children used telemedicine as shown in Table 2. None of the respondents chose lack of internet access or appropriate devices as reasons for not using telemedicine either before or during the lockdown.

3.8 Caregivers' perceptions regarding access to medical care during lockdown

Fifty-six percent of caregivers perceived no change in ease of access to medical care for their children during the lockdown as compared to before the lockdown, whereas 36% felt that access became harder and 8% easier. Additionally, 65% reported that they faced no difficulties with accessing medical care or information about the pandemic. We analyzed the association between level of education and insurance status with regard to the ease of access to medical care and did not find any statistically significant correlation.

3.9 | Sources of health care information during lockdown

Caregivers most commonly obtained information about COVID from social and broadcast media (77%), online reading (43%), their PCP (27%), and the NYC COVID hotline (25%).

3.10 Caregivers' solutions to prepare for future health emergencies

Suggestions from caregivers on what measures would be helpful in caring for their children should there be another future pandemic or

lockdown included the following: more telemedicine with PCPs (60%), PCPs' offices remaining open (41%), and specially designated hospital areas for patients without COVID-19 (47%).

4 | LIMITATIONS

There are multiple limitations to our study.

The study consisted of a self-administered survey of caregivers who brought their children to the PED for acute medical care. There is inherent bias in the sampling of this population as they are already seeking health care in the PED. Caregivers were informed that assistance was available from physicians, nurses, and research assistants, if needed. However, because of social distancing mandates and hospital regulations during the height of the COVID-19 pandemic while this study took place, we had to deliberately limit face-to-face interactions with caregivers. This may have increased the risk of caregivers' misunderstanding of questions or providing inaccurate responses in ways that are not measurable. On the other hand, bias can also be introduced when surveys are filled out by research personnel instead of study subjects themselves.

A strength of our study is that we provided the survey in both English and Spanish, the 2 languages used by the vast majority of the patient population in our PED. However, some inaccuracies may have been introduced due to remaining language barriers and we were unable to recruit from the very small number of caregivers in our PED who speak neither of those 2 languages.

Because completion of every question was not mandatory, participants were able to skip questions, resulting in a small number of responses for some of the survey items.

As our study was conducted over several months after the lockdown period, recall bias may have affected caregivers' responses to questions regarding medical care during the lockdown.

This study used a convenience sample of caregivers in the PED. Although we know the total number of children 0–17 years seen in the PED during the study period was approximately 11,500, we did not collect information regarding the total number of caregivers offered the opportunity to participate in the survey and the rate of refusal. This limits our ability to accurately assess whether the study sample is representative of the overall PED population at that time. We do know that our study population is similar in ethnicity to the usual PED patient composition before the pandemic.

Caregivers completed the survey anonymously. We did not collect contact information and therefore could not send reminders for study completion after the PED visit, which might have negatively affected the completion rate. Although a reminder might have increased the survey completion, this also risked privacy issues. By not collecting any personal information, we were able to obtain expedited IRB review and approval to conduct this study.

Our study cohort consisted of caregivers who presented to an urban PED, of predominantly Hispanic ethnicity, mostly with public insurance and with no reported barriers to internet access or devices.

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Therefore, our findings may not be generalizable to other populations and geographic regions.

5 | DISCUSSION

Beginning in March 2020, the COVID-19 pandemic brought a steep decline in all PCP and PED visits across the United States, including those in New York City.^{4,5} Although others have described changes in health care use during the pandemic based on retrospective aggregated data derived from electronic health information systems,⁵ to our knowledge, this is the first prospective study to directly survey caregivers who brought their children to an inner-city PED in the United States about their perceptions and health care use during the COVID-19 pandemic. This is significant because our study was conducted during the height of COVID-19 when most research was shut down and all non-essential personnel were banned from the hospital. Our study contributes to a better understanding of caregivers' rationales for using the PED as opposed to other in-person and virtual platforms to access medical care for their children's illnesses during the initial wave of the COVID-19 pandemic. Lessons learned from our study may improve planning for better delivery of care for patients in future health crises.

5.1 | Acute medical care before and during lockdown

Almost a quarter of our caregivers reported that their children were sick during the NYC lockdown period at the time of the initial wave of the pandemic, and over 90% sought acute medical care for their children's illnesses. Many of our patients shifted from in-person PCP office visits to virtual telehealth platforms. Caregivers' decision-making was affected by public health care measures and mandates, along with parental fear of contracting COVID infection. We found 2 studies in a recent literature search on caregivers' perceptions on health care use during the height of COVID-19 pandemic. First was by Watson et al. who conducted a semistructured interview of caregivers in an inpatient pediatric hospital in England. The second was by Nicholson et al who conducted a random cross-sectional survey of caregivers in the general population in Ireland.^{8,9} Similar to our study, their caregivers also expressed fears of exposing their children and themselves to COVID as the top concern for not seeking medical care.

It is interesting that despite a third of our caregivers perceiving that access to medical care was more difficult during the lockdown, a large majority of them successfully sought and accessed acute medical care for their sick children when needed. This may be a reflection of our study population sample of caregivers who sought care in our PED. There have been additional large waves of COVID variants and non-COVID viral illnesses since the initial COVID-19 infection. Therefore, it is important that medical systems make the necessary changes to provide safe access to medical care for children. In our population, we found infectious illnesses presenting with fever, respiratory, and gastrointestinal symptoms were the predominant complaints for time periods both during and after the lockdown. These presenting symptoms are similar to those reported in the literature before the COVID-19 pandemic.¹⁰ Even though there was a decline in the total number of acute respiratory illnesses compared to previous years as shown in studies by Haddadin and DeLaroche,^{4,5} we found that these symptoms were still the most common reasons why caregivers accessed medical care for their children during the COVID-19 pandemic. Therefore, infectious illness symptoms appeared to influence caregivers' decision to seek care in a similar manner before and during the NYC lockdown.

5.2 Routine and non-urgent care during lockdown

Published studies have reported significant declines in rates of routine vaccination against multiple different preventable diseases in many countries because of the COVID-19 pandemic.^{11,12} Our study confirmed these findings and in addition found that COVID-19 had a direct negative impact on non-urgent medical care, including scheduled tests as well as routine well-child and specialist visits. The 2 reasons for these declines most cited by our caregivers were closures of PCPs' offices and difficulties in obtaining appointments. These findings are concerning for the possible long-term impacts of the lockdown on children's future health and development.

Maintenance of routine care for children has become even more challenging with continued waves of COVID, putting a strain on medical providers' ability to carry out well-child visits and vaccinations during these surge episodes. Our study highlights the need for creative options to continue to provide routine vaccinations during a pandemic, especially for at-risk minority groups. Some possible solutions for this could include the use of EDs and other public buildings such as churches and community centers that may be easier to access. Even pharmacies are already being used as locations for the administration of emergency COVID-19 vaccines. Expansion of telemedicine across all medical facilities may offer a potential method to facilitate the delivery of primary care as well as continuity of care in future public emergencies.¹³ Advance planning and infrastructure development are urgently needed in order to rapidly respond to any future health care emergencies.

5.3 | Telehealth

Up to 54% of the caregivers in our study used telehealth for their children's acute care needs during the COVID-19 lockdown, representing a shift away from in-person medical visits at PCPs' offices. Our data showed a 5-fold increase in telehealth use during the pandemic. Other studies found an upward trend in telehealth visits as well.^{14,15} Before the lockdown, several barriers to using telemedicine were identified in our study population, mainly the unavailability of telemedicine and

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caregivers not knowing how to use telemedicine. Prior studies have shown that availability of devices and internet access may be barriers to accessing telemedicine services especially among rural populations and socially vulnerable groups.^{16,17} On the other hand, studies looking at urban populations have reported reasonably high rates in ownership of computers and cell phones and access to internet.¹⁸ It is interesting that none of our caregivers identified access to technology as a barrier. These findings highlight the need to advocate on making devices and internet access widely available to the general population including vulnerable subgroups. Additionally, more education to caregivers on how to access telehealth is just as important.

5.4 | Sources of health information during the pandemic

The dramatic decline in PED visits during the COVID-19 pandemic was not seen in the 2009 H1N1 pandemic.¹⁹ This might reflect the much higher level of public health messaging, enforcement, and lock-down measures implemented during the COVID-19 pandemic. Similar to the study by Ali et al²⁰ caregivers in our survey used a wide range of sources to access health information regarding the pandemic, with the news and social media being the most used in caregivers' decision-making process regarding whether to access medical care for their children. This calls attention to the important need for consistent, accurate, and balanced messaging to the public across all sources to educate and inform the public.

In conclusion, during the initial wave of the COVID-19 pandemic, a group of mostly minority caregivers weighed numerous factors in deciding whether or not to seek medical care for their children's acute health issues during the New York State lockdown mandates. Fear of contracting COVID-19 and heeding government advice to avoid health care visits for minor problems were the top reasons for caregivers to not seek medical care, pivoting away from in-person to telemedicine platforms. Our data regarding caregivers' fears and concerns, modalities of care used when accessing medical care during the pandemic and their sources of information can help inform strategies for improved planning for future public health emergencies. Future studies may shed light on the long-term patient health outcomes from these shifts in medical care use during the COVID-19 pandemic and whether these new practice patterns will continue.

AUTHOR CONTRIBUTIONS

Anju Wagh, Shiu-Lin Tsai, Sharon Pan, Stephen Gordon, and Lenka Hellerova conceptualized and designed the study, designed the data collection instruments, collected data, carried out the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript. Henry Park designed the data collection instruments, helped with data and critically reviewed the manuscript for important intellectual content. Yeqing Ji carried out the data analyses and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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CONFLICTS OF INTEREST

The authors have no conflict of interest to declare.

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