Caring for Children With Medical Complexity in the Early COVID-19 Pandemic in an Ambulatory Primary Care Setting

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Background: Children with medical complexity (CMC) have multiple chronic conditions and require a high level of coordinated healthcare. The risk of COVID-19 among CMC is unclear.

Objectives: We aim to identify and describe the prevalence and experience of COVID-19 among CMC and their caregivers during the initial weeks of the COVID-19 pandemic in the NY metropolitan area.

Methods: We performed a cross-sectional study of children enrolled in a structured clinical program for CMC at a large urban, academic general pediatrics practice in NY.

Results: In our patient population (n = 132), 16 patients had a known exposure with parents being the most common exposure in 37.5% (n = 6). Two patients were hospitalized for COVID-19 while the remainder of the confirmed or suspected COVID-19 cases were managed as an outpatient.

Conclusions: Common sources of COVID-19 exposure were family members and home care providers. Almost all of our patients experienced interruption of medical care including missed therapies and visits.

Keywords: children with medical complexity, COVID-19, general pediatrics, complex care, caregivers

INTRODUCTION

The COVID-19 pandemic caused by severe acute respiratory syndrome (SARS-CoV2) is a major health crisis affecting all aspects of society. While COVID-19 infection in the pediatric population appears to have a mild course in comparison to adults, children are still vulnerable to infection and complications (1, 2). Children with medical complexity (CMC) have multiple chronic conditions affecting many organ systems and require a high level of coordinated healthcare (3). Limited evidence to date has shown the most common comorbidity for critically ill children in pediatric intensive care units (PICUs) with COVID-19 is medical complexity (4). Although no studies have yet evaluated the effect of COVID-19 on the CMC population, CMC are generally at higher risk for developing respiratory complications due to factors such as chronic lung disease, impaired airway clearance, and ventilatory support at baseline, likely putting them at increased risk for morbidity.
and mortality from COVID-19. Additionally, CMC typically require multiple therapists, home nurses or home health aides, and case managers, increasing the number of individuals they are exposed to and subsequently their risk of exposure to COVID-19. Finally, missed primary care and sub-specialty appointments due to the COVID-19 pandemic may disproportionately affect CMC, who require significantly more health resources and coordinated healthcare than the general pediatric population.

The goal of this study was to describe the prevalence of and exposure to COVID-19 among CMC and their caregivers and barriers to healthcare that have affected CMC during the early days of the COVID-19 pandemic when stay at home orders were in effect.

METHODS

We performed a cross-sectional study of children (0–21 years) enrolled in a structured clinical program for children with medical complexity at a large urban, academic general pediatrics practice in New York City. All patients enrolled in this program were contacted via telemedicine (audio +/- video) between March 17, 2020 and May 1, 2020. Telemedicine visits were conducted using a predetermined checklist that addressed clinical concerns including COVID-19 and disruptions in care. Demographic data and information regarding COVID-19 status was collected through chart review in our ambulatory electronic medical record (EMR). The study was submitted to Northwell Health's Institutional Review Board (IRB) and was considered exempt.

RESULTS

A total of 132 patients were enrolled in the clinical program for CMC at the time of data collection (Table 1). In our population, 28.8% were Black or African American and 23.5% had a preferred language other than English. Most patients (87.9%) were publicly insured. The most common chronic conditions were: neurologic or developmental disability (81.8%), chronic lung disease (41.7%), and cardiac disease (32.6%). Patients had an average number of 2.2 chronic conditions. The majority of patients were technology dependent, with 56.8% requiring enteral feeding and 35.6% having respiratory support (tracheostomy/ventilator or non-invasive positive pressure ventilation).

Within this patient population, 36 patients developed symptoms associated with COVID-19. Of those, 11 had a known COVID-19 exposure. An additional 5 patients had a known exposure but did not develop symptoms. The most common source of exposure was a parent, followed by in-home care providers (home health aide, home nurse, or therapist) (Table 2). The most common symptoms among this cohort of 36 symptomatic patients were fever, cough, rhinorrhea, and shortness of breath. There were no differences in demographic or clinical characteristics between those with and without a COVID-19 exposure. Two patients were hospitalized for COVID-19. One patient experienced a heart failure exacerbation but did not require any respiratory support and was discharged home. The second patient experienced respiratory failure and eventually died. The remainder of patients with clinical symptoms of COVID-19 (both confirmed and suspected) were managed as an outpatient.

DISCUSSION

This study provides a cross-sectional description of the characteristics and short term outcomes of the early phases of the COVID-19 pandemic on an ambulatory, medically complex, pediatric population in New York City during stay at home orders. Surprisingly, very few of the medically complex patients required hospitalization due to COVID-19 infection. This is in line with the larger body of research showing a milder course and generally good outcomes for COVID-19 infection in the pediatric population (1, 2, 4, 5). Despite this, pre-existing medical comorbidities do seem to play an important role for children that are hospitalized with COVID-19, particularly those who are critically ill (5, 6). One potential protective factor may be the role of the state-wide stay at home orders in the clinical experience of COVID-19 on our CMC. In addition, family caregivers implemented mitigation techniques such as foregoing home services and assuming full-time roles as home nurses and nursing assistants for their children (7). Without this mandate and the diligent safety protocols many families instituted, this cohort may have been more at risk for contracting COVID-19. Furthermore, COVID-19 vaccination is another important mitigation technique. Experts have advocated for prioritizing CMC and their caregivers (given their role as health care personnel) for COVID-19 vaccination and the need to ensure access to vaccination for this population (7, 8). The data described in this study was collected prior to widespread availability of COVID-19 vaccination, but future studies should examine vaccine uptake and its potential protective effects in this population.

CMC represent an important subset of pediatric patients that are susceptible not just to the primary complications of COVID-19 but also the secondary effects of the pandemic (9). Many of the public health measures put into place during the pandemic (social distancing, school closures, reduction in non-urgent health care visits) had unique consequences for CMC. Almost all our patients had medical care that was affected by the COVID-19 pandemic, with interruption of therapies and missed visits being the most common. This likely affects the general pediatric population as well, but may be more impactful for CMC.

The direct and indirect complications of COVID-19 may have been partly attenuated in our study by regularly scheduled, proactive, telephonic outreach to every member of this cohort. Widespread adoption and expansion of telemedicine during the COVID-19 pandemic has shown promise in managing both acute and chronic illness and providing routine care and therapies for patients (10–12). Telemedicine remains a powerful and promising tool to lessen care gaps and access issues.

CMC are especially susceptible to the direct and indirect effects of COVID-19 due to their reliance on a large interdisciplinary, interprofessional care team. During the
TABLE 1 | Demographic and clinical features of patient population.

| Demographics | Total (n = 132) | No COVID exposures (n = 116) | Known COVID exposure (n = 16) | P-value |
|--------------|----------------|-----------------------------|-----------------------------|---------|
| Age (months, mean) (range) | 72.5 (5–121) | 73.0 (5–121) | 68.9 (15–117) | 0.36 |
| Gender (n, %) | | | | |
| Male | 81 (61.3) | 69 (59.5) | 12 (75.0) | 0.23 |
| Female | 51 (38.6) | 47 (40.5) | 4 (25.0) | |
| Race (n, %) | | | | |
| White | 12 (9.0) | 12 (10.3) | 0 (0) | 0.75 |
| Asian | 23 (17.4) | 21 (18.1) | 2 (12.5) | |
| Black or African American | 38 (28.8) | 32 (27.6) | 6 (37.5) | |
| American Indian/Alaskan Native | 1 (0.7) | 1 (0.9) | 0 (0) | |
| Other | 50 (37.9) | 43 (37.1) | 7 (43.8) | |
| Unknown | 7 (5.3) | 6 (5.2) | 1 (6.2) | |
| Ethnicity | | | | |
| Not Hispanic or Latino | 80 (60.6) | 72 (62.1) | 8 (50) | 0.23 |
| Hispanic or Latino | 44 (33.3) | 36 (31.0) | 8 (50) | |
| Unknown | 8 (6.1) | 8 (6.9) | 0 (0) | |
| Preferred Language | | | | |
| English | 102 (77.3) | 89 (76.7) | 13 (81.3) | 0.02 |
| Spanish | 29 (22.0) | 27 (23.3) | 2 (12.5) | |
| Chinese | 1 (0.76) | 0 (0) | 1 (6.2) | |
| Insurance type | | | | |
| Public (Medicaid/CHIP) | 115 (87.1) | 103 (89.7) | 12 (75.0) | 0.23 |
| Private | 16 (12.1) | 12 (10.3) | 4 (25.0) | |
| Other | 1 (0.01) | 1 (0.01) | 0 (0) | |
| Clinical features | | | | |
| Chronic conditions | | | | |
| Neurologic or developmental disability | 108 (81.8) | 94 (81.0) | 14 (87.5) | 0.53 |
| Chronic lung disease | 55 (41.7) | 47 (40.5) | 8 (50.0) | 0.47 |
| Cardiac disease | 43 (32.6) | 39 (33.6) | 4 (25.0) | 0.49 |
| Technology dependence | | | | |
| Oxygen/Trach/Ventilator | 47 (35.6) | 41 (35.3) | 6 (37.5) | 0.87 |
| Nasogastric/Enteral feeding tube | 75 (56.8) | 66 (56.9) | 9 (56.3) | 0.96 |
| # of active medications (mean) | 6.9 | 6.8 | 7.8 | 0.48 |
| # of specialists seen (mean) | 5.2 | 5.1 | 5.4 | 0.61 |
| # of hospitalizations (past 1 year) | 1.9 | 1.9 | 2.25 | 0.56 |
| Total length of stay (LOS) (days) (past 1 year) | 12.7 | 13.6 | 6.4 | 0.36 |
| Ancillary care services (n, %) | | | | |
| Home nursing | 49 (37.1) | 44 (37.9) | 5 (31.2) | 0.60 |
| PT/OT/Speech therapy | 112 (84.8) | 99 (85.3) | 13 (81.3) | 0.67 |
| Health home | 57 (43.2) | 53 (37.1) | 4 (25) | 0.12 |
| Ambulatory care | | | | |
| Contact with clinical team | | | | |
| Patients who engaged in telemedicine (n, %) | 48 (36.4) | 40 (34.5) | 8 (50.0) | 0.23 |
| Mean # of telephonic encounters | 1.36 | 1.10 | 3.19 | <0.005 |
| Mean # of telemedicine visits | 1.02 | 0.86 | 2 | 0.06 |
| Delayed/Canceled In-Person Visits (n, %) | | | | |
| Primary care | 31 (23.5) | 29 (25.0) | 2 (12.5) | 0.27 |
| Subspecialty | 73 (55.3) | 62 (53.4) | 11 (68.9) | 0.25 |
| Postponement of care (n, %) | | | | |
| Vaccines | 8 (6.1) | 6 (5.2) | 2 (12.5) | 0.25 |
| Elective surgical procedures | 4 (3.0) | 4 (3.4) | 0 (0) | 0.45 |
| Routine dental care | 3 (2.3) | 3 (2.6) | 0 (0) | 0.52 |
| Routine eye care | 10 (7.6) | 8 (6.9) | 2 (12.5) | 0.43 |
| Routine laboratory studies | 1 (0.8) | 1 (0.9) | 0 (0) | 0.71 |
| Interruption of home care services (n, %) | | | | |
| Nursing | 7 (5.3) | 6 (5.2) | 1 (6.3) | 0.86 |
| PT/OT/Speech therapy | 14 (10.6) | 13 (11.2) | 1 (6.3) | 0.55 |
| Difficulty obtaining supplies (n, %) | | | | |
| Routine medications or supplies | 9 (6.8) | 8 (6.9) | 1 (6.3) | 0.92 |
| Enteral tube feedings | 10 (7.6) | 9 (7.8) | 1 (6.3) | 0.71 |

# means “number”. 

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TABLE 2 | COVID status of children with medical complexity.

| Most commonly reported COVID symptoms                      | Total n = 35 (n, %) |
|------------------------------------------------------------|---------------------|
| Fever                                                      | 20 (57.1)           |
| Cough                                                      | 13 (37.1)           |
| Rhinorrhea/Nasal congestion                               | 6 (17.1)            |
| Shortness of breath/Difficulty breathing                   | 4 (11.4)            |
| Diagnostic testing (n, %)                                  |                    |
| Confirmed (via nasal swab testing)                         | 5 (14.3)            |
| Required hospitalization (n, %)                            | 2 (5.6)             |

Despite its limitations, this study has several important implications. First, given the high rates of missed care, healthcare providers should focus on minimizing gaps in care for CMC with proactive outreach during the ongoing COVID-19 pandemic and future outbreaks. Second, given the high risk of exposure in parents of CMC, this study suggests the need to identify and train backup caregivers in case a primary caregiver becomes ill.

Third, caregivers should consider the need to balance the risk of exposure from in-home care services with the necessity of the service provided.

Given the wide availability and feasibility of using telemedicine in patients with CMC (15), future directions should focus on expanding telemedicine to bridge care gaps for families. Furthermore, there is a distinct need to organize support for backup caregivers who may be inexperienced. Finally, pediatricians should deliver support for caregivers, who may be strained taking on more roles with limited resources in a pandemic setting.

This study represents the early effects of the COVID-19 pandemic on the CMC population. The emergence of new variants including delta and omicron has led to a rise in pediatric cases and therefore will have implications on CMC, who are more susceptible to progression to severe disease. It is essential that future studies be conducted to determine the ongoing threat of COVID-19 on this vulnerable population.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: Datasets include PHI. Requests to access these datasets should be directed to astakofsky@northwell.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Human Research Protection Program (HRPP) Feinstein Institutes for Medical Research Northwell Health. Written informed consent from the participants’ legal guardian/next of kin was not required to participate in this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

AD, MP, KB, CS, SF, AY, and SJ were involved in the planning, data collection, and authorship of this paper. All authors contributed to the article and approved the submitted version.

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REFERENCES

1. Dong Y, Mo X, Hu Y, Qi X, Jiang F, Jiang Z, et al. Epidemiological characteristics of 2143 pediatric patients with 2019 coronavirus disease in China. Pediatrics. (2020) 145:e20200702. doi: 10.1542/peds.2020-0702

2. Choi SH, Kim HW, Kang JM, Kim DH, Cho EY. Epidemiology and clinical features of coronavirus disease 2019 in children. Clin Exp Pediatr. (2020) 63:125–32. doi: 10.3345/cep.2020.00535

3. Chiang J, Amin R. Respiratory care considerations for children with medical complexity. Children. (2017) 4:41. doi: 10.3390/children4050041
4. Shekerdemian LS, Mahmood NR, Wolfe KK, Riggs BJ, Ross CE, McKiernan CA, et al. Characteristics and outcomes of children with coronavirus disease 2019 (COVID-19) infection admitted to US and Canadian pediatric intensive care units. *JAMA Pediatr.* (2020) 174:868–73. doi: 10.1001/jamapediatrics.2020.1948

5. Ludvigsson JF. Systematic review of COVID-19 in children shows milder cases and a better prognosis than adults. *Acta Paediatr.* (2020) 109:1088–95. doi: 10.1111/apa.15270

6. Gonzalez-Dambrauskas S, Vasquez-Hoyos P, Camporesi A, Díaz-Rubio F, Piñeres-Olave BE, Fernández-Sarmiento J, et al. Pediatric critical care and COVID-19. *Pediatrics.* (2020) 146:e20201766. doi: 10.1542/peds.2020-1766

7. Murphy N, Darrow N. Parents of children with medical complexity are essential health care personnel. *Pediatrics.* (2021) 147:e2021050160. doi: 10.1542/peds.2021-050160

8. Lakhany D, Shaw E, Strockwell M. Facilitating COVID-19 vaccination among caregivers of children with medical complexity. *Clin Pediatr.* (2021) 60:497–500. doi: 10.1177/000992282111036273

9. Wong C, Ming D, Maslow G, Gifford EJ. Mitigating the impacts of the COVID-19 pandemic response on at-risk children. *Pediatrics.* (2020) 146:e20200973. doi: 10.1542/peds.2020-0973

10. Onofri A, Pavone M, De Santis S, Verrillo E, Caggiano S, Ullmann N, et al. Telemedicine in children with medical complexity on home ventilation during the COVID-19 pandemic. *Pediatric Pulmonol.* (2021) 56:1395–400. doi: 10.1002/ppul.25289

11. Garg A, Goyal S, Thati R, Thati N. Implementation of telemedicine in a tertiary hospital-based ambulatory practice in Detroit during the COVID-19 pandemic: observational study. *JMIR Public Health Surveill.* (2021) 7:e21327. doi: 10.2196/21327

12. Camden C, Silva M. Pediatric telehealth: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. *Phys Occup Ther Pediatr.* (2021) 41:1–17. doi: 10.1080/01942638.2020.1825032

13. Temsah M, Alhboob A, Abouammoh N, Al-Eyadhy A, Aljamaan F, Alasheem F, et al. Pediatric intensive care hybrid-style clinical round during COVID-19 pandemic: a pilot study. *Front Pediatr.* (2021) 9:720203. doi: 10.3389/fped.2021.720203

14. Mersky J, McKelvey L, Janczewski C, Fitzgerald S. Effects of COVID-19 on home visiting services for vulnerable families: a cross-state analysis of enrollment, engagement, and attrition. *Fam Syst Health.* (2021). doi: 10.1037/fsy0000667

15. Notario PM, Gentile E, Amidon M, Angst D, Lefaiver C, Webster K. Home-based telemedicine for children with medical complexity. *Telemed J E Health.* (2019) 25:1123–32. doi: 10.1089/tmj.2018.0186

Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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