Purpose of review
Coronavirus disease 2019 (COVID-19) has exposed the vulnerabilities of children with medical complexity (CMC). This article uniquely describes how pediatric providers in various clinical settings can adapt routine healthcare maintenance visits to meet the needs of CMC in the era of COVID-19. We also discuss unique visit components important to address when providing primary care to CMC, including caregiver support, disaster preparedness, long-term care planning, and telemedicine.

Recent findings
Although some children may be less severely affected by COVID-19 than adults, current literature suggests that CMC may be at higher risk for severe disease. In addition, the COVID-19 pandemic has highlighted the value in consistent, primary care for CMC. Children, especially those with medical complexity, are at risk for interruptions in care, delayed vaccinations, increasing caregiver burden, and barriers to in-person care.

Summary
This article summarizes the components of the healthcare maintenance visit for CMC, providing salient recommendations on how pediatric providers can adapt their approach to the primary care of CMC in the era of COVID-19.

Keywords
children with medical complexity, coronavirus disease 2019 pandemic, healthcare maintenance
particularly vulnerable to these changes. The COVID-19 pandemic also ushered in a new era for telemedicine – presenting a breadth of opportunities to address access and transportation concerns. In this article, we discuss how COVID-19 exposed vulnerabilities in the care of CMC and present ways that pediatric primary care providers in various clinical settings can adapt routine healthcare maintenance visits to meet the needs of CMC and their families in the era of COVID-19. We also emphasize special considerations important to incorporate into providing primary care for CMC, including caregiver support, disaster preparedness, long-term care planning, and telemedicine.

DEFINING CHILDREN WITH MEDICAL COMPLEXITY

Various definitions of CMC exist in the literature, but a widely accepted framework defines CMC as children having: substantial family-identified service needs; diagnosed or undiagnosed chronic conditions which are severe; severe functional limitations; and high healthcare use [1]. There are approximately 320,000–560,000 children in the United States who meet the above definition of CMC and the prevalence is increasing. In addition, although CMC account for only 6% of the Medicaid population, they generate 40% of child Medicaid expenditures [2]. Providers frequently feel uncomfortable caring for CMC in clinical practice, despite the high medical need and cost of CMC [3].

CMC require extensive care management from multiple medical and community providers, and often rely on technology such as feeding tubes or home ventilators. They are at risk for high emergency room use, prolonged hospitalizations, and frequent readmissions [4,5]. According to United States data, CMC are twice as likely to have an unmet health need [6]. Furthermore, while CMC interact frequently with their ambulatory primary and specialty care providers, many have inconsistent visits specifically focused on preventive care, which makes this subset of children more likely to be hospitalized [7,8]. It is critically important to recognize that primary care providers are uniquely positioned to support the health and well being of CMC through their ability to develop trusting relationships with the families and to greatly assist with medical decision-making by clarifying goals and circumstances specific to each child and family [7].

CORONAVIRUS DISEASE 2019 AND CHILDREN WITH MEDICAL COMPLEXITY

The pediatric population is thought to be less often affected by the COVID-19 virus than the adult population. As of December 31, 2021, pediatric cases account for 17.4% of current COVID-19 cases [9]. Symptoms of COVID-19 in children have often been reported as mild. Fever, cough, headache, and diarrhea were the most frequently reported symptoms. Less than 3% of pediatric cases resulted in severe disease requiring oxygen supplementation, and <1% were deemed critically ill [9,10,11]. Current literature recognizes a subset of pediatric patients that may be at higher risk for significant morbidity and mortality- including children with medical complexity (Table 1). To date, there are no published data for the prevalence of COVID in these children with underlying co-morbidities.

Although the COVID-19 pandemic overall had a notable decrease in pediatric emergency room visits, the proportion of children with chronic medical conditions receiving care through the emergency room actually increased [12]. This trend could support the concept that children with medical complexity utilize healthcare differently.

Table 1. Risk factors for severe COVID-19 in pediatric patients

| Risk Factor                          |
|-------------------------------------|
| Infants under 1 year of age         |
| Asthma or chronic lung disease      |
| Diabetes                            |
| Genetic, neurologic, or metabolic conditions |
| Sickle cell disease                 |
| Congenital heart disease            |
| Immunosuppression                    |
| Medical complexity                   |
| Obesity                             |

Source: CDC Accessed July 21, 2020 (https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#ChildrenAndTeens). COVID-19, coronavirus disease 2019.
In addition to the morbidity and mortality of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus that causes COVID-19, many additional social and environmental factors made the pandemic very challenging for CMC and their families. The families of CMC frequently rely on community-based supports to provide necessary services and therapy. Each child and family had to weigh the perceived necessity of those services against the fear of viral spread through the community. Indeed, schools are an important source of care, services and respite for families, making their closure particularly difficult for these vulnerable children. Access to gloves and cleaning supplies, which are especially essential for technology-dependent children, became scarce and difficult to obtain. There were interruptions in primary and specialty care as well as delayed procedures and vaccinations.

**ADDRESSING THE PRIMARY CARE NEEDS OF CHILDREN WITH MEDICAL COMPLEXITY: ADAPTING IN THE ERA OF CORONAVIRUS DISEASE 2019**

The American Academy of Pediatrics (AAP) has set forth guidelines through *Bright Futures* that define the components of a preventive pediatric healthcare visit, which include monitoring of growth and development and anticipatory guidance. In addition, quality measures for the primary care of complex pediatric patients have been previously published [13]. These expand on the *Bright Futures* guidelines to include additional components relevant to CMC such as care coordination and shared decision making with caregivers. Given the impact of the COVID-19 pandemic, we focus on six specific elements that pediatric primary care providers should focus on and adapt during routine primary care visits for CMC: vaccinations, development, family support, long-term care planning, telemedicine, and disaster planning in the following sections. (Table 2)

### Office visits

CMC have frequent medical needs and points of access with the healthcare system (i.e., emergency rooms, specialists). Although continuity of care is important for every patient, its value here cannot be underestimated or undervalued. Primary care physicians should have regularly scheduled visits with their medically complex patients, especially in times of crisis. Care for CMC should aim to be proactive, not reactive. In order to fully accommodate the needs of these patients, longer appointments likely should be planned (30–60 min is often ideal). It is also often helpful to schedule complex patients at slower times in the office, for example, at the beginning of the day. Common practice is to schedule these visits according to patient need and diagnosis – as often as 1–2 weeks for unstable, new diagnoses, but no longer than every 6 months for stable patients with competent families. These additional visits are used to complete medication reconciliation, review care with their specialists and to assess other family needs.

Even the most stable, complex patients can become critically ill very quickly. These patients need after-hours access to their primary care physicians who know them well and are comfortable with their needs. They also require same day visits when sick and a care coordination team that can assist with medical transport. An effective primary care pediatrician will have an appropriate number of complex patients based on the size of office and having a support team in place. Direct
communication with the specialists taking care of the child also is helpful. Frequent, focused visits allow the physician to know the patient well, anticipate recurrent issues, ideally prevent unnecessary hospitalizations and improve quality of life. When emergency room visits and hospitalizations do occur, these patients need timely follow up after discharge. Transport is frequently an issue for these patients, so provider flexibility in scheduling is important. During the COVID-19 pandemic, families of CMC frequently have chosen to limit contact with medical care due to concerns for exposure to SARS-CoV-2 virus. We recommend thinking creatively and flexibly about appointment times, locations and alternate strategies (i.e., telemedicine, phone triage) to meet the needs of the most fragile patients.

Before history taking and physical examination occur, adapting the physical space of the office for these patients is an important consideration. These patients often come with equipment (e.g., wheelchairs, ventilators, tube feedings) and several caregivers (e.g., parent, nursing, transportation providers). It is important to have a space large enough to accommodate them comfortably. CMC may need to travel with multiple adults to care for them, so exceptions should be made to assist them. In addition, basic measurements like heights and weights are often challenging to perform. Equipping your office with a wheelchair scale is ideal, but may not always be practical. Training staff on safe transfers between exam table and wheelchair is necessary. Stacking your office with the appropriate rescue needs (e.g., Ambu bag, suction equipment, oxygen) is also important.

As with all patients, a complete and thorough physical exam is necessary. Patients in a wheelchair or stretcher should be examined on the examination table, if a safe transfer can be provided. A skin exam is of particular importance- assessing for skin breakdown around pressure points (i.e., occiput, sacrum, wrists, knee, and ankles) and around technology (i.e., the trach stoma and gastrostomy tube site). Practitioners also should assess a patient’s medical equipment for signs of misuse and breakdown as part of the physical exam. If developmentally capable, patients should be involved in the exam. In all cases, a slower pace, narration of the process, and sharing results may be beneficial to the patients and families.

Vaccinations
The vaccine record should be reviewed at each visit, irrespective of the original purpose of the appointment. Vaccines are often delayed or missed in complex patients due to frequent specialist visits, prolonged illnesses, or hospitalizations. Patients should be vaccinated, as appropriate, according to the CDC schedule [14]. Exemptions for vaccines (i.e., immunosuppression) should be reviewed regularly to determine current status. Care should be taken to ensure patients receive the pneumococcal, quadrivalent meningococcal, and meningococcal B vaccines, as indicated. These vulnerable patients should also receive the flu vaccine each year, early in the season. The HPV vaccine should be given on time; no assumptions need to be made about a patient’s future sexual encounters. All eligible patients should be encouraged to get the COVID-19 vaccine. Especially, important for CMC is ensuring that all caregivers are also vaccinated against COVID-19. Caregivers may have concerns about administering vaccines to their medically complex children. Therefore, providers should initiate and engage in open discussion of the risks and benefits of all vaccines, specific to their child.

Development
CMC frequently experience developmental delays and often require physical, occupational, and speech-language therapies. The COVID-19 pandemic has led to disruptions in the delivery of these therapeutic supports either with complete halting of these services due to staffing shortages or the conversion of these therapies to virtual platforms. These interruptions to therapy can have significant consequences on the long-term development of CMC. In a survey of 207 parents of children with disabilities, 27–35% of parents reported that their child was not receiving their recommended therapies either through early intervention or school-based services during the COVID-19 pandemic. Furthermore, 44% of parents reported low satisfaction with their children’s services during the COVID-19 pandemic. Receiving virtual therapies positively predicted overall satisfaction for parents whereas receiving school-based therapies negatively predicted overall satisfaction [15]. Much of the burden of these therapies has also been pushed toward already overwhelmed parents. In a survey of 207 parents of children with disabilities, 27–35% of parents reported that their child was not receiving their recommended therapies either through early intervention or school-based services during the COVID-19 pandemic. Furthermore, 44% of parents reported low satisfaction with their children’s services during the COVID-19 pandemic. Receiving virtual therapies positively predicted overall satisfaction for parents whereas receiving school-based therapies negatively predicted overall satisfaction [15]. Much of the burden of these therapies has also been pushed toward already overwhelmed parents. In a survey of parents of children with physical disabilities in France, up to 60% of parents performed their children’s therapy [16].

It is not yet clear what the long-term consequences of these therapy disruptions will be on children, particularly those who are medically complex. However, it is essential that during routine healthcare maintenance visits, primary care providers assess the developmental milestones of each patient and ask about whether therapies have continued and in what format. It is helpful for practices to develop collaborative partnerships with local therapy providers, including early intervention, local school districts, and private therapists.
Family and caregiver support

Families are a crucial part of the care coordination for CMC because they are responsible for managing coordination between multiple specialists on their own. This became even more striking during the pandemic. Because of the necessity and frequency of acute care services for CMC, such as sick appointments and hospitalizations, family must be well equipped to deal with issues as they arise. Although data on caregivers and caregiving responsibilities during COVID-19 have been limited, a study on children with autism spectrum disorder during the pandemic reported higher levels of anxiety in caregivers than in their children [17]. As a result of the physical and emotional burden placed on family caregivers, it is important to provide families with the communication and support they require.

Effective communication with families is one of the quality measures for the primary care of CMC [13]. Some ways to improve communication between the medical team and caregivers include utilizing telephonic and telemedicine encounters and using HIPAA (The Health Insurance Portability and Accountability Act - a US federal law to protect sensitive patient health information from disclosure without patient consent)-compliant virtual patient portals to enable easy access to appointments and medical records. Additional interventions to reduce caregiver stress include: care coordination models, respite care, peer support, and insurance and employment benefits [18].

Despite the need for effective communication, caregivers of CMC report that providers vary in their ability to meet linguistic or cultural needs and awareness of community resources [19]. In some circumstances, connecting families of CMC with other families dealing with similar situations can be helpful [19]. It is important to recognize that care of the family is critical because it is linked to the health of the child [20]. Families play a big role in care coordination and effective care coordination can positively impact the care of medically complex children [21]. During routine healthcare maintenance visits with CMC, providers should ask caregivers about their existing supports and provide local and national resources such as support groups and counseling, when appropriate. Ensuring that each caregiver is connected with adult primary care helps facilitate this process.

Long-term care planning

Because CMC are living longer thanks to medical advances, there is a greater need for long-term care planning, which includes the variety of services required to meet a person’s health or personal care needs during a short or long period of time. The importance of having a care plan in place was highlighted during the COVID-19 pandemic. Most families agree that planning for the future is important, yet a significant portion of families are neither willing nor ready to make future plans due to a lack of awareness, services, and social supports. Long-term care planning is important, so physicians should connect their families with care managers or social workers to begin the conversation around future plans.

Telemedicine

Telemedicine has grown in popularity in recent years, especially since the beginning of the COVID-19 pandemic. This is a product of the continued increase in technological knowledge and smartphone availability [22]. This progress was accelerated by the COVID pandemic, which loosened the restrictions that could be used on telemedicine platforms. In addition, changes to reimbursement, which favored telemedicine as a means to continue care when in-person visits were not possible, expanded connectivity. Prior to the COVID-19 pandemic, studies confirmed the efficacy of telehealth visits for CMC [22]. These studies revealed that telemedicine works especially well for this population, with minimal connectivity issues, and significant cost savings per patient due to lower numbers of hospitalization days despite an increase in the number of acute and telehealth visits [22]. In a study with 73 telehealth encounters among 24 patients, device connectivity was successful 96% of the time and image and sound quality were acceptable in 98% of visits [22]. These initial studies suggest that telemedicine is feasible for CMC and that successful connectivity is possible with appropriate support.

There are significant differences between perceived and demonstrated understanding around medications. Telemedicine could offer potential benefit for medication regimen comprehension. Since patients are in their own homes, their medications are readily available to reference during the visits. A cross-sectional study done in a complex care clinic found that only 73% of parents correctly identified medications, 40% could identify complete dosing parameters, and only 55% could correctly measure two doses [23]. Therefore, the access to the home environment that telemedicine provides could help close these gaps by creating opportunity for caregivers and providers to review and reinforce important aspects of medical management with all supplies and medications easily accessible.

The pandemic also provided an opportunity to expand upon telemedicine studies in order to prepare for future situations when CMC cannot make it into the office for in-person checkups. Video telehealth
visits were shown to be both feasible and easily integrated into existing complex care frameworks [24]. Flexibility with visits from home facilitates continuity of care post hospitalization, when the child is in a more fragile state, by removing transportation barriers [24]. Furthermore, the use of a telemedicine platform can also enable multiple providers to simultaneously meet with patients and their caregivers, facilitating the development of better coordinated interdisciplinary specialty care for CMC.

During telemedicine visits, physicians should follow the same clinical guidelines that they would during an in-person visit. It is crucial to instruct the family to prepare the patient beforehand, making sure he or she is in front of the camera and that all medicines are easily accessible. If possible, provide the family with instructions to take some vitals before the meeting to optimize time during the virtual visit. This may include the patient’s heart rate, oxygen saturation, and temperature.

During the virtual visit, make sure to use a HIPPA-compliant platform, preferably using video. In contrast to audio-only telephone calls, videos are optimal because they give a bidirectional interaction between families and physicians [24]. This may ultimately improve family engagement in the child’s care and as a result, amplify the care coordination process [25]. Physicians will also be able to see a patient’s home set up and therefore, can offer suggestions to help families optimize their home environment. In cases where video platforms are not an option, conducting a visit via the telephone should be considered.

After the visit, follow-up must be arranged to ensure well coordinated care. A clinical team member should connect with caregivers to ensure the care plan discussed during the telemedicine visit is being executed properly. For example, a clinical team member can call caregivers to confirm follow-up appointments and diagnostic studies are scheduled. In cases where there is an acute clinical concern, any changes in signs or symptoms should be discussed and escalated to a higher level of care such as an in-person office visit or, if needed, an emergency room visit. The importance of postvisit follow-up after a telemedicine visit cannot be underscored enough.

**Disaster planning**

The COVID-19 pandemic has highlighted the need for continual ‘disaster planning’ for this medically fragile population. The lessons learned during the pandemic can be applied to various scenarios. It is important to instruct families to have a plan in place just in case regular care is disrupted. Physicians should instruct patient families to create a clear plan that includes clinically important physicians and their contact information, possible at home care providers, and medications needed to prepare for unexpected circumstances. A list of back-up care providers who are trained appropriately is important, not only if staffing shortages, but also due to the possibility of the primary caretakers becoming ill. It is also important to confirm families have enough medications and medical equipment in case of a lack of access to pharmacies or medicines. Families and backup caregivers should also be educated and prepared to use telemedicine, whether by smartphone, computer, or telephone as necessary.

**CONCLUSION**

The care of CMC requires a thoughtful balance between addressing the patients’ chronic medical conditions as well as routine preventive care. In particular, the complexity of this care has been highlighted during the COVID-19 pandemic, increasing the burden of care on both families and providers. Our goal in this article is to provide a framework for consideration in approaching the healthcare maintenance visit of CMC and adapting it to the changing times during COVID-19.

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**Conflicts of interest**

There are no conflicts of interest.

**REFERENCES AND RECOMMENDED READING**

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- **of outstanding interest**

1. Cohen E, Kuo D, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics 2011; 127:529–538.

This watershed paper establishes a working, multifaceted definition of CMC and sets the foundation for pursuing care and research in this fragile population.

2. Berry J, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Milwood) 2014; 33:2199–2206.

3. Altman L, Zuriyndi Y, Breen C, et al. A qualitative study of healthcare providers’ perceptions and experiences of working together to care for children with medical complexity. BMC Health Serv Res 2018; 18:70.

4. Collier R, Nelson B, Sklansky D, et al. Preventing hospitalizations in children with medical complexity: a systematic review. Pediatrics 2014; 134:e1628–e1647.
5. Kuo D, Berry J, Glader L, et al. Health services and healthcare needs fulfilled by structured clinical programs for children with medical complexity. J Pediatr 2016; 169:291.e1–296.e1.
6. Kuo D, Goudie A, Cohen E, et al. Inequities in healthcare needs for children with medical complexity. Health Affairs 2014; 33:2190–2198.
7. Lee K, Hill D, Feudtner C. Decision-making for children with medical complexity: the role of the primary care pediatritian. Pediatr Ann 2020; 49: e473–e477.
8. Shumsky I, Richardson T, Brar S, et al. Well child visits of Medicaid-insured children with medical complexity. J Pediatr 2018; 189:223.e2–230.e2.
9. Children and COVID-19: state-level data report. American Academy of Pediatrics. 2022. Available at: https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/children-and-covid-19-state-level-data-report/.
10. Al horme F, Temsah M, Al-Nemri A, et al. COVID-19 infection prevalence in pediatric population: etiology, clinical presentation, and outcome. J Infect Public Health 2020; 13:1791–1796.
11. Yasuhara J, Kuno T, Takagi H, Sumimoto N. Clinical characteristics of COVID-19 in children: a systematic review. Pediatr Pulmonol 2020; 55:2565–2575.
12. DeLaRoche A, Rodean J, Aronson P, et al. Pediatric emergency department visits at US children’s hospitals during the COVID-19 pandemic. Pediatrics 2020; 147:E2020039628.
13. Chen A, Schrager S, Mangione-Smith R. Quality measures for primary care of complex pediatric patients. Pediatrics 2012; 129:433–445.
14. Immunization schedules. Centers for Disease Control and Prevention. 2021. Available at: https://www.cdc.gov/vaccines/schedules/index.html.
15. Murphy A, Pinkerton L, Bruckner E, et al. The impact of the novel coronavirus disease 2019 on therapy service delivery for children with disabilities. J Pediatr 2021; 231:168.e1–177.e1.
16. Cacioppo M, Bouvier S, Baily R, et al. Emerging health challenges for children with physical disabilities and their parents during the COVID-pandemic: the ECHO French survey. Ann Phys Rehabil Med 18:101429.
17. Amorin R, Catarino S, Miragaia P, et al. The impact of COVID-19 on children with autism spectrum disorder. Rev Neurol 2020; 71:285–291.
18. Edelstein H, Schipkie J, Sheffe S, et al. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev 2017; 43:323–333.
19. Lakshmanan A, Kubicek K, Williams R, et al. Viewpoints from families for improving transition from NICU-to-home for infants with medical complexity at a safety net hospital: a qualitative study. BMC Pediatr 2019; 19:223.
20. Curran MA, Minoff E. Supporting children and families through the pandemic, and after; the case for a US child allowance. Soc Sci Humant Open 2020; 2:100040.
21. de Banate MA, Maypole J, Sadof M. Care coordination for children with medical complexity. Curr Opin Pediatr 2019; 31:575–582.
22. Notario PM, Gentile E, Amidon M, et al. Home-based telemedicine for children with medical complexity. Telemed J E Health 2019; 25:1123–1132.
23. Blackmer AB, Fox D, Arendt D, et al. Perceived versus demonstrated understanding of the complex medications of medically complex children. J Pediatr Pharmacol Ther 2021; 26:62–72.
24. Ross MH, Parnell LS, Spears TG, Ming DY. Telemedicine video visits for children with medical complexity in a structured clinical complex care program. Glob Pediatr Health 2020; 7: 2333794X20952196. Describes the ease and practicality of integrating video calls into routine visits to positively affect the care of medically complex children and theorizes on its possibility for future use.
25. Whitehead L, Jacob E, Towell A, et al. The role of the family in supporting the self-management of chronic conditions: a qualitative systematic review. J Clin Nurs 2018; 27:22–30.