



# Beyond the First Wave: Consequences of COVID-19 on High-Risk Infants and Families

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## Abstract

The novel coronavirus disease 2019 (COVID-19) pandemic is affecting care for high-risk newborns in ways that will likely be sustained beyond the initial pandemic response. These novel challenges present an urgent imperative to understand how COVID-19 impacts parent, family, and infant outcomes. We highlight three areas that warrant targeted attention: (1) inpatient care: visitation policies, developmental care, and communication practices; (2) outpatient care: high-risk infant follow-up and early intervention programs; and (3) parent psychosocial distress: mental health, social support, and financial toxicity. Changes to care delivery in these areas provide an opportunity to identify and implement novel strategies to provide family-centered care during COVID-19 and beyond.

## Keywords

- ▶ family-centered care
- ▶ communication
- ▶ telemedicine
- ▶ parent mental health

## Key Points

- The COVID-19 pandemic is influencing care delivery for high-risk newborns and their families.
- Rapid changes to care delivery are likely to be sustained beyond the initial pandemic response.
- We have an urgent imperative to understand how COVID-19 impacts infant, parent, and family outcomes.

The novel coronavirus disease 2019 (COVID-19) has introduced profound changes to health care delivery across the world. Strategies to mitigate spread have varied by unit, region, and country. Neonatal intensive care units (NICUs) have worked to balance safety with providing family-centered care by implementing new visitation policies, changing the format of team and bedside communication, and embracing opportunities to connect virtually with patients and families.

To date, COVID-19 research has largely concentrated on the adult population and has focused on the epidemiology of the

disease, improving testing methodologies, potential therapies, and vaccine development. Research specific to neonatal-perinatal medicine has thus far centered on advancing our understanding of perinatal and postnatal severe acute respiratory syndrome-coronavirus-2 (SARS-CoV-2) transmission, pregnancy outcomes, disease severity among infected newborns, and hospital personnel and equipment shortages.<sup>1,2</sup>

The impact of SARS-CoV-2 on the risk of preterm birth is unknown, though maternal SARS-CoV-2 infection and related complications have influenced delivery decision making

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for some patients.<sup>3,4</sup> Current data suggest that vertical transmission of SARS-CoV-2 may occur, but the direct impact of maternal, fetal, or neonatal SARS-CoV-2 infection on neonatal outcomes is unknown.<sup>5-8</sup> The downstream effects of the COVID-19 pandemic have included hospital and outpatient clinic policy changes and restricted presence of parents at the bedside, resource and services access challenges for children with special health care needs, and financial, employment, and housing losses for families.

The COVID-19 pandemic is affecting care for high-risk newborns in considerable ways that will likely be sustained beyond the initial pandemic response. These novel challenges present an urgent imperative to understand how COVID-19 impacts parent, family, and infant outcomes. Here, we highlight three areas that warrant targeted attention: inpatient care, outpatient care, and parent psychosocial distress.

### **Inpatient Care: Visitation Policies, Developmental Care, and Communication Practices**

Many obstetrical and NICU wards have changed visitation processes to mitigate the spread of COVID-19. Some obstetrical units have limited visitors at the time of birth, requiring expectant parents to make choices between partners, doulas, extended family members, and other sources of support.

Many NICUs have also instituted visitation policies (for example, limiting visitors to one per infant). Although such policies are evolving, data obtained from respondent attendees in an ongoing series of COVID-19 webinars, developed by the California Perinatal Quality Care Collaborative (CPQCC),<sup>9</sup> reveal that nearly all responding California NICUs have changed their family visitor policies, with almost half requiring one family member to be designated as the single visitor allowed for the entire hospitalization.

Parent-driven interventions have a positive impact on infant and parent outcomes. Infants who experience early skin-to-skin contact experience less pain, have improved neurodevelopmental outcomes and growth, and experience less physiologic instability.<sup>10-16</sup> Parent engagement in infant clinical care improves parent mental health outcomes<sup>11,16-18</sup> including symptoms of anxiety and depression. Existing data suggest that parents who participate in clinical care feel more competent, bonded with their infant, and prepared for life at home.<sup>19-21</sup> Changes in visitation policies and care delivery may have a host of downstream consequences such as decreased parent presence at the bedside, decreased engagement in clinical care, and decreased readiness for home.

Decreased parent presence at the bedside has changed the ways in which teams can communicate with families. Daily updates and discussion of major changes to care may occur virtually or by phone. Family conferences, which are often an opportunity for parents to interface with multiple care team members at once, may occur less frequently or be transitioned to a virtual format. Many family conferences typically include team members with expertise and training to provide immediate emotional support to parents in distress. It is

unclear if these services are as accessible or effective in a virtual format. In situations where only one family member can be present at an infant's bedside at a time, the family member may need to relay medical information to other loved ones. Existing data suggest that parents may feel burdened by the responsibility of translating medical information to their partner or other family members.<sup>22</sup>

Although not equivalent to bedside presence, one potential adaptation to increase parent participation amidst visitation restrictions is using technology to facilitate virtual participation of parents in rounds, major conversations with the team, and care at the bedside. The degree to which NICUs have implemented these types of programs is unclear. Of CPQCC survey participants, over one-third responded with concerns that technology to accommodate parents' virtual presence was not available or significantly limited.<sup>9</sup> Parents' access to devices at home was likely also variable and rapid deployment of virtual health care delivery has the potential to exacerbate existing inequity. How parents participate in, engage with, and perceive virtual communication with their infant's care team is unknown.

Changes to parent participation in clinical care and parent presence at the bedside may be particularly relevant as patients and families transition to home. Discharge teaching typically requires in-person education of all caregivers who may be caring for the child. While some elements of discharge teaching may be amenable to virtual instruction, others require hands-on manipulation of equipment or medication. Visitor restrictions may make it challenging for all infant caregivers to receive in-person instruction. Ongoing work should evaluate whether such changes influence length of stay, parent confidence, and parent self-efficacy.<sup>23-25</sup> These changes present an opportunity to introduce and study the impact of online education resources.<sup>26</sup>

### **Outpatient Care: High-Risk Infant Follow-up and Early Intervention Programs**

Changes to care delivery are not limited to the inpatient setting. Many outpatient pediatric clinics have embraced telemedicine to deliver care by phone or video-assisted communication; however, access to and implementation of telemedicine is highly variable. These changes have been implemented widely across a broad range of disciplines critical to the care of high-risk infants, including neurodevelopmental follow-up, pediatric specialty, and primary care clinics. This practice change is reflected in [▶Fig. 1](#), which summarizes the transition from in-person to a mix of in-person, telephone, and video visits at Duke Children's General Pediatrics and Pediatric Subspecialty Outpatient Clinics.

Access to telehealth infrastructure and appointments likely varies across regions and centers, for example, between large urban centers, suburban communities, and rural areas. The burden of decreased availability of in-person services is likely to fall disproportionately on children with complex health care needs, who interface with the health care system frequently across multiple clinics and whose medical needs may be less amenable to virtual

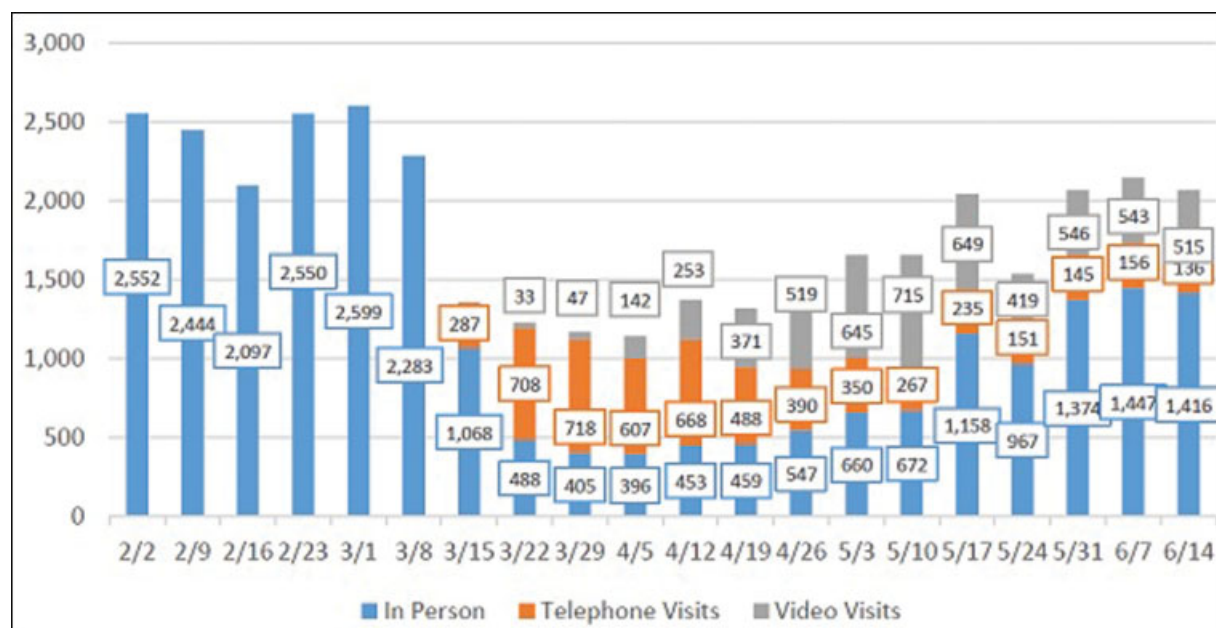


Fig. 1 In person, telephone, and video outpatient arrived visits within Duke Pediatrics.

management.<sup>27</sup> Children with a history of preterm birth are more likely to require rehabilitation therapy services after discharge.<sup>28</sup> Early intervention programs improve infant motor and cognitive outcomes.<sup>29</sup> While some stages of the early intervention process may be amenable to virtual delivery, others benefit from or require face-to-face contact. Engaging with young patients and those with cognitive impairment may be particularly challenging in a virtual setting.

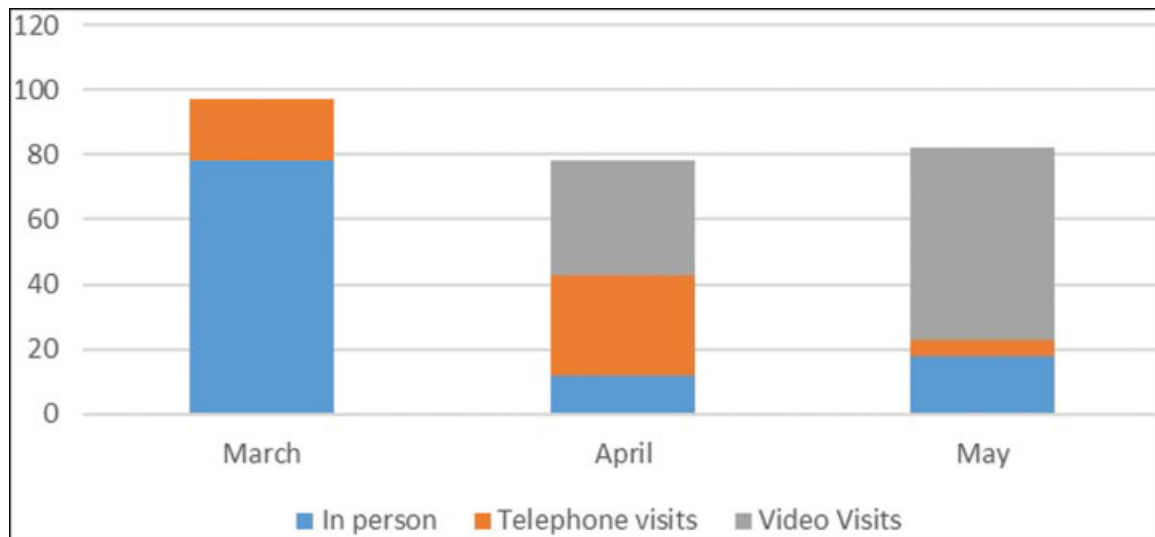
Clinics and parents have been required to weigh in real time in which visits are “essential” and whether to defer care for elective procedures. It is unknown whether decreased in-person visits, including routine well-child care, will result in delayed presentations of illness, decreased immunization rates, or increased morbidity. High-risk infant follow-up is central to the longitudinal care of infants discharged from the NICU and is recommended by the American Academy of Pediatrics and other expert groups.<sup>30,31</sup> These programs provide an interprofessional, multidisciplinary approach to the care of high-risk infants that facilitates early identification of neurodevelopmental impairment and timely referral to needed services.<sup>32,33</sup> Attendance in high-risk infant follow-up clinics that support early intervention services improve infants’ neurodevelopmental outcomes<sup>34,35</sup> and serve as touch points for clinical and research programs. Recent initiatives to integrate standardized motor assessments into high-risk infant follow-up assessments have resulted in shortened time to the diagnosis of cerebral palsy.<sup>36</sup> Importantly, access to high-risk infant follow-up is not uniform; a large, population-based cohort of extremely low birth weight infants demonstrated an association between socioeconomic factors and attendance in high-risk infant follow-up.<sup>37</sup>

Programs that offer enhanced support around the transition from the NICU to home can decrease infant rehospitalization rates and overall health care costs.<sup>38,39</sup> These

programs may have added benefit during the COVID-19 pandemic, when parents may have less time at the bedside to prepare for life at home. The value of comprehensive medical home programs, which often include increased access to NICU clinicians, should be studied in the setting of decreased in-person access to specialty providers. Within Duke Neonatology’s comprehensive medical home program, a rapid transition to video telehealth visits maintained a clinic schedule of approximately 75% in the early months of the COVID-19 outbreak (→ Fig. 2). This group, which provides parents with around-the-clock pager access to providers in NICU follow-up clinic, also saw a dramatic increase in pager activity during the early stages of the crisis from concerned parents hoping to obtain medical advice without going to urgent care centers.

The COVID-19 pandemic has highlighted existing racial and social disparities in health outcomes. Many fear that the rapid and broad scale implementation of telemedicine in response to COVID-19 may widen disparities in access to health care for vulnerable populations who may have limited access to technology or limited English proficiency.<sup>40</sup> Up to 25% of the population has limited digital literacy skills or access to appropriate internet bandwidth to allow participation in a video-enabled telemedicine visit.<sup>41,42</sup> Nouri and colleagues recommend that hospitals proactively evaluate their telemedicine system to identify and eliminate inherent barriers to access.<sup>40</sup>

Increased use of telehealth services, in both the inpatient and outpatient setting, has the potential to benefit many infants and families, especially those burdened by challenges with transportation, childcare, and chronic medical needs. The rapid uptake of such services in the setting of COVID-19 provides an opportunity to understand how to deploy telemedicine services responsibly and sustainably beyond the COVID era. Meeting goals of perceived patient experience



**Fig. 2** Outpatient arrived visits for Duke Division of Neonatology.

metrics, along with potential institutional financial benefits, may result in broad telehealth deployment without evidence-based understanding of risks and benefits.

### Parent Psychosocial Distress: Mental Health, Social Support, and Financial Toxicity

In even the most routine of times, the NICU is a stress- and anxiety-provoking place for parents. For parents of children born extremely preterm, the NICU is the location of what is likely one of the most traumatic experiences in the life of their family.<sup>23</sup> At baseline, parents of babies in the NICU are at significantly increased risk of depression, anxiety, and trauma, which can persist for long periods after discharge.<sup>43</sup> As many as two in three mothers of preterm infants in the NICU have depressive symptoms, and up to half have symptoms of anxiety. Approximately one in four parents will experience symptoms of posttraumatic stress.<sup>44–47</sup> Neonatal clinical factors alone are not sufficient to predict which parents will experience mental health challenges; Shaw et al<sup>47</sup> found no relationship between maternal symptoms of posttraumatic stress in the NICU and a wide range of neonatal clinical variables. These data argue for the importance of routine mental health screening in parents of premature infants.

Peer support programs can mitigate mental health challenges experienced by parents.<sup>48–53</sup> Many face-to-face peer support programs rely on volunteer support and include parent gatherings; most NICUs have suspended these activities in the setting of COVID-19 restrictions. This void highlights the potential role of virtual peer support programs; clinicians should actively connect parents to relevant organizations.

Parental symptoms of anxiety, depression, and posttraumatic stress can extend far beyond the NICU stay and can have profound impacts on relationships, communication, and parenting. High-stress and trauma symptoms among mothers in the NICU are associated with dysfunctional coping and increased perception of child vulnerability later

in life.<sup>44,54,55</sup> Existing data additionally suggest that poor parent mental health outcomes are associated with worse childhood developmental outcomes including cognitive, behavioral, and fine motor challenges.<sup>56,57</sup>

The COVID-19 pandemic crisis is likely to have a substantially additive effect on the stressors already felt by our patients' families in the NICU and in the community. Mental health challenges are not isolated to parents in the home and may affect siblings and other caregivers. Survey data from more than 2,300 school-aged students confined to home during the height of the crisis in China's Hubei province revealed that nearly one in four had symptoms of depression, and one in five had symptoms of anxiety.<sup>58</sup> Previous epidemics, including SARS and H1N1, resulted in increased rates of depressive and posttraumatic stress symptoms, and some studies suggest increased risk of substance dependence and abuse.<sup>59,60</sup>

Families may also be facing broader challenges that undermine their ability to care for a high-risk infant. Family financial constraints and resource limitations may result directly in housing insecurity, food insecurity, and the inability to obtain social supports. The disruption in the social support structure due to the need for social distancing may increase feelings of isolation and depressive symptoms in caregivers. Obtaining safe childcare may be challenging; many parents may be unable to rely on family and friends due to social distancing constraints. Financial distress may amplify parent mental health challenges. Data from previous pandemics suggest that financial loss is a risk factor for symptoms of depression, anxiety, and posttraumatic stress.<sup>61–63</sup> Fortunately, several evidence-based treatments effectively address the psychological distress experienced by parents of preterm infants.<sup>24</sup>

The COVID-19 pandemic has precipitated an abrupt but successful transition to telehealth services in the mental health field. For those with access to technology, telehealth delivery of mental health services may relieve barriers to accessing care due to travel challenges, time constraints, or other logistical concerns. For others, lack of access to

adequate technology may limit their ability to receive necessary care at a time of heightened risk.

## Conclusion

The COVID-19 pandemic and necessary mitigation strategies have introduced significant changes to care delivery for high-risk infants and their families. These changes provide an opportunity to identify and implement novel strategies to provide family-centered care to support families during COVID-19 and beyond.

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### Conflict of Interest

None declared.

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