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Seeking Normalcy as the Curve Flattens: Ethical Considerations for Pediatricians Managing Collateral Damage of Coronavirus Disease-2019

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Fearful. Uncertain. Overwhelmed. Committed. Hopeful. Pediatricians around the world have cycled through these emotions when considering the health and safety of patients and families during this coronavirus disease 2019 (COVID-19) pandemic. We worry about the direct medical effects of COVID-19. We also worry about the ancillary effects of the lockdowns, stay-at-home orders, closed clinics, schools, and daycare centers, and newly unemployed parents on the well-being of children. We focus on those concerns. We believe that responding to these ancillary effects of COVID-19 will be a bigger challenge for pediatricians than the clinical care of children with COVID-19. These challenges will be with us for the foreseeable future.

Introduction

The COVID-19 pandemic presents quickly evolving ethical challenges for pediatricians. Some of the issues are not specific to COVID-19. They include moral distress, reprioritizing clinical goals, responding to unique vulnerabilities of children, addressing uncertainty in shared decision making, and considering how and when to proceed with pediatric clinical research. COVID-19 puts a new spin on all of them. It also offers opportunities to rethink solutions. How we respond matters. We must use the challenges of this pandemic as opportunities to improve the health of our children now and even after COVID-19 recedes. This pandemic highlights long-standing deficiencies and inefficiencies in our current system of child healthcare. As advocates for children, pediatricians are in a unique position to redesign the system in a way that prioritizes children and families, addresses the social determinants of health, decreases inequalities and health disparities, and ensures ethical research on the treatment and prevention of COVID-19.

Moral Distress and Utilitarian Prioritization in the Throes of Crisis

The COVID-19 pandemic has created experiences of moral distress in our lives at home, in the clinical setting, and as citizens in our communities.[1] Moral distress is the psychological discomfort experienced when we feel that we must act in ways that violate our own deep moral commitments. As clinicians and as members of communities in this pandemic, our actions have initially and rightfully centered on crisis-mode utilitarian goals of saving the most lives. However, actions to conserve the medical resources that prevent iatrogenic spread of infection and protect health professionals and other patients have shifted priorities away from the best practices that are part of our usual care for children. We are committed to holistic and family-centered care. But the conditions of the pandemic constrain us; we cannot do what we know is best. Therein lies our distress.

We all prioritize goals of care within resource constraints. However, pandemic-era care is different in 2 ways. First, prioritization in the midst of a pandemic considers foremost the overall needs of groups of people, instead of our usual prioritization of the individual person in front of us. Second, the limited resources we must protect include us as healthcare workers. We are uncomfortable delaying a reintubation to don personal protective equipment, even though we know we must protect ourselves so that we can continue to treat our patients. We similarly worry about the patients we do not see because of decreased staffing levels in our clinics, or because families opt to reasonably defer medical care because of stay-at-home orders or fear of getting infected in a clinic.

In our communities, we are conflicted in our inclinations to "reopen" or to remain "sheltered." We know lives have been saved by nonpharmaceutical interventions like transmission prevention measures. That said, we also recognize that many people have suffered because of school, business, and government shut downs. There are clearly trade-offs. If everyone stayed home all the time, no one would become infected with COVID-19. But our children would not be educated, our stores would not be stocked, and our economy would grind to a halt. We seek the optimum balance between the risks of infection and the risks of perfect protection.

Our hearts ache for all children, but especially for those who have situational vulnerabilities that put them at greatest risk of adverse effects both from illness and from a shut-down society. Situational vulnerabilities are conditions such as

COVID-19 Coronavirus disease 2019

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The authors declare no conflicts of interest.

https://doi.org/10.1016/j.jpeds.2020.06.067

poverty or family instability that can worsen how individuals experience problems such as the current pandemic. These vulnerabilities deserve special ethical consideration because they often exist owing to societal injustices.[2] Whether children are our patients or are outside of our immediate communities, we feel a sense of responsibility and with that, a deep uncertainty and powerlessness. We may not always know the best course of action, but we must help to find that balance. We will gradually move out of a crisis mode, and we can begin to shape a new normal right now.

Shifting Clinical Goals to Address Our Patients' Vulnerabilities

As we begin to imagine that new normal, we consider 3 domains that require attention to help children to stay well: medical, mental health, and educational needs.

Medical Needs

During the COVID-19 crisis, many hospitals and clinics have limited procedures, numbers of staff, and patients, cancelling elective surgeries and nonessential pediatric visits.[3] Although this step was necessary to decrease the risk of inadvertently spreading the virus and to conserve personal protective equipment, these practices have had unintended negative consequences. Children have experienced delays in clinical care. Immunization rates have decreased.[4] Children are at risk for health problems that are not directly related to COVID-19, but that are a result of our necessary response to the pandemic.

Pediatricians and pediatric subspecialists are now required to triage patient procedures and visits, raising the question of what, exactly, is "elective." Some surgical procedures that can be delayed without an immediate risk to the life or health of the patient may still have adverse consequences from waiting, as in the case of pyeloplasty and adolescent herniorrhaphy.[5-7] Lengthy delays already exist for families trying to gain access to pediatric subspecialty appointments, such as for children with cleft palate.[8] Such delays increase anxiety and stress for families and could result in a worsening of the patient's clinical condition.[9,10] Temporary cessation of home health services for children with chronic medical conditions may increase the occurrence of acute-on-chronic complications. Infants experiencing postponement of necessary early intensive developmental supports (eg, speech and language therapy, occupational therapy, physical therapy) may lose a benefit proven to support their development, possibly lengthening time to advancement and/or stunting their ability to reach their true potential.[11]

To overcome COVID-19-mediated effects on medical care, primary care pediatricians, and pediatric subspecialists can respond with several measures. Outreach to check-in on patients and families regarding both their physical and mental health, will reestablish connections, nurture trust, and allow personalized counseling about needed services.[12] Virtual in-home physical, occupational, or speech therapies can keep children on track. Primary care pediatricians, pediatric subspecialists, and pediatric surgeons must collaborate and carefully monitor all patients whose treatment was postponed to ensure that they are not getting worse.[13,14] Communicating with patients on processes to make clinic visits safe may reassure anxious parents. All pediatricians should notify families about the options to connect with their care providers whether in person or via telephone, email, or telemedicine.[15,16] Mobile clinics to reach children in underserved areas could decrease lags in immunizations.[17] Sometimes, home visits with adequate personal protective equipment might be necessary. Finally, in looking further ahead, pediatricians can collaborate with allied healthcare professionals to facilitate "catch up" on the inevitable wait lists for those providers who have been limited to providing emergency services.[18,19]

Alongside medical needs, pediatricians understand the relevance of social factors to their patients' health.[20,21] Medical providers must acknowledge and address the needs of children whose situational vulnerabilities put them at greatest risks of harm during this pandemic.[22] Such consideration is critical to prevent further widening, and to ideally narrow, existing health and socioeconomic disparities. The pandemic has already drastically altered fundamental disparities in the social determinants of health, defined by the World Health Organization as "conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life."[23] There are ways that pediatricians can respond to mitigate the harmful effects of these changes, but we will need to be creative and proactive. We can leverage existing partnerships or forge new ones to best meet the needs of our patients and their families. For example, medical-legal partnerships are local links between medical professionals and legal advocates. They can protect low-income families' legal rights that may be at risk in the current pandemic. They can help to guard against eviction and utility shut-offs, help families navigate public benefit sign-ups, and ensure access to critical educational resources.[24] Other clinical-community partnerships (eg, with food banks) may have a similar, bold effect.[25,26] Pediatricians may refer families to key social service agencies within their community that are responding in earnest to COVID-19's harmful effects (eg, United Way 211, a free resource that can link families to local resources).[27] We can also avail ourselves to help community groups that may benefit from a clinician's assistance.[28]

Mental Health Needs within Families

Children in families with mental health needs will be vulnerable to further disruptions to their psychosocial stability owing to COVID-19 control measures. Shuttered community resources upon which people rely increases the risk for the most vulnerable children. A family member with mental illness or substance misuse may therefore experience barriers to their own usual coping supports. These barriers could further endanger children in the home. These circumstances can all contribute to a dangerous escalating cycle if a family's coping skills were already precarious.[29]

Stress also increases the risk of child maltreatment. Rates of physical abuse increase during periods of economic crises and after natural disasters.[30,31] Maladaptive disciplinary behaviors, which put families at risk for escalating violence in the home, increase during recessions.[32] Because child sexual abuse is often perpetrated by someone known and trusted by the child, stay-at-home orders may increase perpetrators' access to children. Abuse may go unreported, however. We were concerned to learn that, during the early weeks of the recent stay-at-home orders in Illinois, there were sharply decreased call volumes to child maltreatment hotlines.[33] We suspect that this is the result of children isolated from teachers, counselors, and health providers like pediatricians who typically generate most of the reports.[34] Not all abuse is going unnoticed, however. A tip line for reporting of online sexual exploitation of children noted a 5-fold increase in calls.[35]

Social distancing also affects visitation and placement for youth entering foster care. For those children who require alternative safe placements or children who need to be removed from a home owing to maltreatment, foster parents and extended family members may be more hesitant to increase COVID-19 exposures by accepting new children and child protection caseworkers into their homes.

For many children, mortality and illness are unfamiliar concepts and they will be especially vulnerable to the psychological stresses caused by the disturbing news and images generated by stories about COVID-19.[36] Children may also see their parents worrying for the first time about their families' medical and economic health. Some children may find themselves in difficult situations from being forcedly separated from one parent (eg, children of separated couples or with a parent in jail).[37] Pediatricians can provide education to parents on using honest, age-appropriate language to discuss difficult topics such as disturbing news stories, illness, death, and unemployment. Parents and older children can also learn from their pediatricians about moderating screen time and video gaming to minimize maladaptive effects on neurocognitive development, obesity, body malposition, and eye problems.[38-40]

Pediatricians need to review their records, identify children with mental health concerns or a history of maltreatment, and reach out to the families of these children. Self-care to mitigate anxiety and stress will be protective and can build resilience.[26] Pediatricians can proactively provide education on mental health and effective discipline strategies.[41] Parents can also be directed to sites of professional organizations such as the American Academy of Pediatrics' HealthyChildren.org. Pediatricians can connect patients to mental health professionals who develop and disseminate mental health interventions to support families with pandemic-driven stresses.[42-44]

Educational Needs

Some children's educational needs will be fulfilled more easily than others with the transition to learning at home. Children with access to technology—personal devices and local Internet connectivity[45]—may make the transition to home-based or electronic learning more easily. Children who usually receive learning accommodations in the classroom may find that their needs are not easily met with technology, further widening educational gaps between them and their peers.[46] The so-called summer slide—the loss of educational progress—may be accelerated, and may persist, for as long as children find themselves homebound. Children with autism or special needs who are unable to adhere to their routines may have particular difficulty during shelter-in-place regulations, and we can direct families to resources in their areas.[47,48] Pediatricians may be able to assist schools in finding children (eg, >2000 in Chicago) whom educators have been unable to be contact since the start of the pandemic.[49]

Advocating for the Most Vulnerable Children

Although all children are at risk for challenges during the pandemic, poor children are at greater risk. Poverty makes shelter-at-home regulations more difficult.[50,51] The risks are both medical and nonmedical. COVID-19 infection and death rates are higher among people of color and those of low income.[52] Factors at the root of this disparity include densely populated living areas (where disease transmission is overall more prevalent), suboptimal housing, and more difficulties meeting basic needs.[53,54] Elderly family members living in multigenerational homes will be at greatest risk of severe illness. Children with limited safe outdoor spaces and cramped living quarters may have adverse psychological effects, and prolonged exposure to indoor pollutants and pests may exacerbate medical problems.[55-57] Many children normally receive nutrition at school—with free or reduced-price breakfast and lunch—a provision that continues in many cities despite school closures.[58,59] Access to cleaning supplies, masks, and hand sanitizer may also be more challenging for families with limited financial means or private transportation.[60]

Outside of our clinics, we can address these situational vulnerabilities that put children at risk by advocating in the public policy arena. We can work for housing-related programs with medical-legal partnerships. We can advocate for employment protections, paid sick leave regulations, and economic stimulus for those most in need.[61] We can similarly lend our voice to food access programs for children and families, partnering with those who distribute public benefits and with businesses and nonprofits that bolster the underlying safety net.[30] During the quarantine, many families have discovered that their homes are better-suited to sleep in rather than to live in continuously. Online lessons have been challenging or impossible for children, because most families live in 2- or 3-room homes where isolation and silence are impossible. Over the longer term, we can advocate to city and building planners to design living spaces that allow easier social distancing in future pandemics with family-friendly areas for safe physical activity. We as pediatricians may not always be the ones in the lead, but we can

always be in support, helping to prioritize fundamental needs for those most at-risk populations.[22,39,62]

Uncertainty and Ethics Guiding Research about COVID-19

Because COVID-19 is new, we do not yet understand the natural history or the factors that influence prognosis. We do not yet know the best treatments. Everything is innovative. If we had more time, we could do more studies, but the rapid spread of the pandemic makes that impossible. We do not yet understand all of the ways the virus is transmitted, the best practices to slow or halt transmission, the range of illness manifestations, or the sensitivity and specificity of different diagnostic tests.

We desperately need more research on all aspects of this new disease. The international medical community has adapted quickly to collect data and disseminate findings to help guide clinical practices. We are beginning to understand COVID-19's clinical course. We are identifying complications afflicting certain children, like the Kawasaki disease-type sequelae after COVID-19 infection now being called multisystem inflammatory syndrome in children.[63,64] Registries now enable sharing of data to better elucidate perinatal transmission and COVID-19 illness in newborns.[65] In the meantime, when we talk to families, we must be transparent about our knowledge gaps while still providing best evidence to parents when sharing decisions for the care of their children. Guidance from professional organizations can support discussions with COVID-19 positive mothers deliberating between postdelivery separation from newborns and cautious "rooming in" and directly breastfeeding vs providing expressed breastmilk. Screening, tracing, and asymptomatic transmission require elucidation to inform which practices will best prevent transmission of the virus in daycare, school, and sports settings so that we can help guide parents and administrators institute safe plans for reopening.[66]

The zeal for learning how to combat COVID-19 will require temperance, however, with ethical principles that govern research in nonpandemic-related areas.[67] As investigators develop studies to test new treatments, they will need to clearly explain what is known, what is not known, the reasons why research is being done, the risks and benefits of participating in research, and the risks of being treated with therapies that have not been validated by rigorous clinical studies. There is no risk-free choice between participation in clinical research or opting for standard care when there is no standard of care. With either choice, parents may have unrealistic expectations about risks and benefits. Doctors must guide them to understand the risks and benefits of either option.

The ethics of research will become more complicated as candidate vaccines enter clinical trials. Vaccine studies are technically and ethically complex. Studies require large numbers of participants to assess both efficacy and safety. Rushing development and endorsement of a COVID-19 vaccine before establishing efficacy and safety could endanger not only recipients, but also the uptake of current safe vaccines.[68] However, holding off on vaccine use while completing studies will be stressful for both doctors and families. Pediatricians will need to help design studies in ways that minimize risk and generate useful data as quickly as possible, and then help families to understand the choices that they face.

Conclusions

Children have encountered and will continue to encounter unique challenges as the COVID-19 pandemic continues. We cannot ignore discrepancies in social determinants of health. Keeping families and communities safe and our patients healthy is no small task. But we have an opportunity, if we pay close attention to the vulnerabilities exposed by this pandemic, to make conditions better for children than before the pandemic began.[69-71]

Justice is a key value. We need to be attentive to health disparities as we develop new programs to respond to COVID-19 and COVID-related health challenges. Pediatricians have a fiduciary responsibility to each patient and family that they serve, but they also have a broader responsibility to the population of children in our communities. We must ensure that no subgroup is overlooked or left out. Because some patients suffer unjustly owing to situational vulnerabilities, fairness may require we focus more efforts toward those children at risk of greatest harms. Transparency will mean making clear that, despite uncertainty, our decisions and choices are reasoned, evidence based, and strive for equity. Maintaining rigorous ethical standards for research will produce knowledge we can confidently endorse. The positive downstream effects of early interventions on health are familiar to pediatricians. The challenges are daunting but they are not insurmountable. Pediatricians can transform them into powerful opportunities for improving the lives of children. ■

Submitted for publication May 14, 2020; last revision received Jun 3, 2020; accepted Jun 22, 2020.

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