

Short Communication

Disparities and ethical considerations for children with tracheostomies during the COVID-19 pandemic

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Abstract. The COVID-19 pandemic is exacerbating longstanding challenges facing children with tracheostomies and their families. Myriad ethical concerns arising in the long-term care of children with tracheostomies during the COVID-19 pandemic revolve around inadequate access to care, healthcare resources, and rehabilitation services. Marginalized communities such as those from Black and Hispanic origins face disproportionate chronic illness because of racial and other underlying disparities. In this paper, we describe how these disparities also present challenges to children who are technology-dependent, such as those with tracheostomies and discuss the emerging ethical discourse regarding healthcare and resource access for this population during the pandemic.

Keywords: COVID-19, ethics, pediatric tracheostomy, chronic disability

1. Introduction

The COVID-19 pandemic is exacerbating longstanding challenges facing children with tracheostomies and their families. Children with tracheostomies have comorbid conditions and require complex healthcare delivery services [1–4]. Personnel and adequate tracheostomy supplies to prevent complications and maintain wellness are critical for these children [5,6]. Many ethical concerns arising in the long-term care of children with tracheostomies during COVID-19 revolve around inadequate access to care, healthcare resources, and rehabilitation services.

Marginalized communities such as those from Black and Hispanic origins have been reported to face disproportionate chronic illness because of racial and other underlying disparities during the pandemic in the adult world [7,8]. We postulate that such disparities also impact children who are technology-dependent, such as those with tracheostomies. This paper will explore how racial disparities and societal inequities have framed the emerging ethical discourse regarding healthcare and resource access for this population and how as a result, the pandemic has limited and will likely continue to limit access to medical services for children with tracheostomies.

2. Disparities and ethical considerations

There is a collective ethical duty to care for those infected with COVID-19 as well as those with other

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medical problems. As medically fragile children depend on technology and well-trained caregivers, there is a special duty to ensure their safety and take special steps to minimize harms. Due to their frequent comorbidities [2,3], children with tracheostomies will be at greater risk for worse outcomes compared to their peers if they become infected with the virus [9,10]. They will also likely require additional healthcare resources including personnel, durable medical equipment, and personal protective equipment in the hospital. As SARS-CoV-2, the virus causing COVID-19, is spread through respiratory droplets and caring for tracheostomies requires manipulation of the aerodigestive tract, there is an increased infection risk for caregivers and providers [11]. From not only an ethical but a public health standpoint, ensuring children with tracheostomies stay out of the hospital during the pandemic stands to benefit all of society.

The caregivers of children with tracheostomies will invariably experience hardship navigating the health-care system and in their day-to-day lives during the pandemic. This hardship may likewise extend to children and young adults as they are inherently vulnerable due to their disability [12] and require additional resources to combat physical, emotional and developmental challenges [13]. Barriers to communication and their need for constant caregiver support are examples of these vulnerabilities. With hospital policies limiting access to patient visitors, barriers to communication are exaggerated, making it challenging for these children to advocate for themselves [14]. Any restrictions on patient visitors will limit the potential for additional support that multiple caregivers at the bedside might well provide [15]. Further, because children with tracheostomies require extensive human support, caregivers who cannot work from home or work in high-risk infection jobs may experience challenges in providing optimal and safe homecare.

Certain children with tracheostomies may further experience compounded disparities during the pandemic. While 29% and 22% of the population in New York is comprised of Hispanic and Black people, respectively, they account for 34% and 28% of COVID-19 deaths [8]. In Michigan, while only 14% of the population is Black, 41% of COVID-related deaths are in Black patients [8]. The infection and death rate from COVID-19 in Black communities in the United States is estimated to be about 3 and 6 times higher, respectively [7]. It is hypothesized that differences in infection and death during pandemics are due to disparities in exposure risk, comorbid conditions and access to treatment for those of

certain ethnic backgrounds [16,17]. Black communities, which have been historically marginalized, have disproportionately been affected by the pandemic, likely as a result of discrimination and long-standing societal inequities from institutional, interpersonal, and structural racism [8,17]. Examples of these inequities include limited choices in housing leaving families to live in crowded apartments where social distancing is not possible, limited access to healthy foods due to food deserts and reliance on buses and subways for transportation [8,17].

While the demographic characteristics of children with tracheostomies are heterogeneous, there are data to suggest that underlying racial disparities are compounded amongst this population and their likelihood of adverse outcomes are also worse, which is particularly concerning during this pandemic. One study using a national database that is presumed to be an approximation of the U.S pediatric inpatient population reported that 21% of children who undergo tracheostomies are Black and 20% Hispanic, clearly disproportionate to the US population [18]. Hispanic infants with tracheostomies also had an increased likelihood of mortality [19]. While the cause for this increased likelihood is not elucidated in the study and is likely multifactorial, their adverse event rates were also higher in comparison to non-Hispanic patients [19]. These pre-COVID-19 data collectively confirm that disparities already impact children with tracheostomies.

For children with tracheostomies and their families from marginalized backgrounds, these issues can translate to other problems and risk factors pertinent during the pandemic, including food insecurity and ability to work from home. Uneven access to the Internet can negatively impact accessing telehealth visits, which can ultimately affect progress with ventilator weaning and titration of settings. Even practicing safe social distancing for children with tracheostomies can be a matter of privilege. Further, because children with tracheostomies require constant care, this can make it challenging for financially strained caregivers to tend to basic household needs, such as having access to healthy foods. As a result, the effect that the virus has on marginalized communities for adults will most certainly carry over to the care of their children [20].

Addressing societal disparities is a core tenet of public health ethics [21]. There is an ethical duty for providers and policy makers to understand how health-care disparities impact vulnerable communities, such as children with tracheostomies. Victims of the virus and the nation's response to it have showcased the in-

herent institutional, interpersonal, and structural racism present today [17]. The disproportionate suffering of marginalized communities due to long-standing inequities serves as a sobering reminder of how much work is still left to be done as a nation to achieve fairness and equity when it comes to caring for society's most vulnerable [17,20,22]. While legal and policy measures can be implemented to mitigate disparate outcomes, such as with regards to access of treatments and vaccines, in the short-term, this response is insufficient; only when interventions are aimed at addressing the true sources of inequity can health justice be achieved for all [17].

3. Manpower

Because children with tracheostomies require extensive caregiver support, ensuring adequate human capital to care for these children during the pandemic should be a priority and especially for those from underrepresented populations. First, homecare nursing is vital for managing tracheostomies [5,23–25]. For children, pediatric-specific home health services are already stressed and often non-existent outside of major cities and their immediate surrounding counties [26]. However, the pandemic has, more broadly speaking, raised issues over access to safe homecare nursing due to infection transmission and inadequate personal protective equipment for home and visiting health staff [27,28]. While limited data exist regarding homecare nursing infection rates, healthcare workers have been demonstrated to be vectors of transmission globally, comprising 9% of infections in Italy [29], and 14% in Spain [30]. Without access to safe homecare nursing and personal protective equipment for nursing staff, children with tracheostomies can be at risk for infection, positioning not only themselves at risk, but their entire family unit. This can be especially problematic for families who chose to forgo homecare nursing over concerns of infection transmission, placing additional burden and stress on caregivers who are also the breadwinners [31].

Second, access to hospitals and specialist clinics has also impacted follow-up care for children with tracheostomies during the pandemic. For example, elective surgical procedures such as reconstructive surgeries for decannulation and tracheotomy revisions or removals are being postponed or cancelled [32]. While telehealth services are being used in these settings [33] the importance of in-person multidisciplinary care remains

irreplaceable. For example, as a tracheostomy impairs speech, the rehabilitative services offered by speech language pathologists are crucial towards restoring essential communication [14,34]. Since supervision and training are needed when trialing speaking valves [34], the services offered by these providers are difficult to substitute via a virtual visit alone. Further, school cancellations mean that children with tracheostomies have likely lost access to the benefits of in-person individualized education programs, services that offer one-to-one nursing staff in addition to many other resources to ensure effective learning experiences for children with disabilities [35].

Finally, the impact the pandemic has had on families is massive. Caregivers are vital to providing care to children with tracheostomies, which includes conducting regular respiratory assessments, tracheostomy tube suctioning, other procedures and providing care during a medical emergency [5,6]. However, for families who do not have the luxury to work from home or are at risk of infection because of their occupation, caring for children with tracheostomies will undoubtedly be compromised. The role that racial disparities have in this context is particularly relevant, as Black workers are more likely to be employed in professions requiring contact, with 20% of Black workers being able to work from home compared to 30% of white workers [36].

4. Ethical decision-making when advocating for justice

The fluctuating global supply chain due to COVID-19 has threatened access to durable health equipment [28,37]. While concerns have centered on ventilator and personal protective equipment shortages [28, 37], the destabilization of the supply chain can cause bottlenecks and shortages in other healthcare sectors as well [38,39]. As a result, this can translate to shortages of essential equipment to care for tracheostomies in the long-term.

Children with tracheostomies require numerous supplies, such as suction machines, portable nebulizers, suction catheters, spare tracheostomy tubes, and a process to order supplies from a supply manager [5,23]. During the pandemic, tracheostomy supplies may not be available to patients due to shortages and delivery delays [31]. Equipment shortages of inner cannulas, humidifiers and suction catheters, have forced supply companies and all involved in the supply chain to think of creative solutions to extend the use of supplies

through home reprocessing techniques and equipment-changing regimens, ultimately causing concern for infection and equipment failure [31]. Due to concerns over access to care and resources for children with tracheostomies during the pandemic, discussing the role of ethical decision-making in resource allocation for this population is crucial.

Proactive and transparent discussions incorporating ethical principles such as beneficence, nonmaleficence, autonomy and justice are emphasized by ethicists and providers in the creation of guidelines for resource allocation during a pandemic response [40,41]. However, schemas that incorporate quality of life presumptions are problematic for many with disabilities, and by extension, children with tracheostomies [42]. The “disability paradox” was coined to highlight the discordance between people with disabilities and people without disabilities when reporting a disabled person’s quality of life [43]. In healthcare, those with disabilities may report their quality of life to be superior to what is anticipated by providers [44,45]. Thus, when practitioners and policy makers are empowered with formulating decision-making protocols for who can have access to supplies and medical services, children with tracheostomies may be negatively impacted by such triage policies [42]. From a disparity perspective, attempts towards crafting objective ethical allocation schemas are likely not sufficient if social determinants of health are overlooked. Racial and ethnic disparities in access to care and health outcomes are constant reminders of how inequities in service and social injustices across communities still perpetuate and compromise the health of those most vulnerable [46]. Discrimination has the potential to creep into poorly designed triage protocols that more or less designate a child with a tracheostomy as having a potential contraindication to accessing a scarce resource. Society will undoubtedly grapple with how strategies that prioritize utility and equality will compromise those most vulnerable [41].

While many rationing schemas are formulated within hospital systems, a great deal of rationing also occurs upstream. Children with tracheostomies are likely grappling more with issues of resource access from the supply side as outpatients rather than from within hospital systems. Vendors and government agencies may be competing with one another for access to these scarce resources [28,37,47]. Uneven access to care translates on a systems level for children with tracheostomies: companies with more power, privilege and money are better positioned to acquire access compared to others who are less connected [41]. These issues will be fur-

ther augmented for children who are victims of racial and socioeconomic disparities.

To mitigate these concerns, routine communication amongst government, hospitals, and supplier companies might ensure equitable and consistent approaches to rationing schemas across cities and states. Increasing representation of children with tracheostomies and their caregivers to elevate their voices during policy discussions can be integral towards promoting a patient-centered approach to solve these issues [42]. Finally, efforts directed towards collecting data on parameters that are known to be influenced by disparities, such as race, would be beneficial so that scarce resources can be optimally deployed to communities most in need [17,36].

5. Conclusion

COVID-19 is straining the contemporary healthcare system in ways previously unimaginable. Children with special needs, including those with tracheostomies, are disproportionately experiencing issues related to inadequate access to care. The impact the pandemic has on children with tracheostomies merits reflection on how long-standing racial disparities and societal inequities frame the ethical discourse regarding resource allocation and healthcare access. An ethical duty lies herein to recognize that in addition to responding to the acute care needs of COVID-19 positive patients, children with tracheostomies and other children with special needs also face ongoing challenges during the pandemic in the form of difficulties acquiring the healthcare services and supplies necessary for optimal health, growth, and development. Providers and policy makers are well-positioned to advocate for the rights and health of children with tracheostomies to ensure fair and equitable access to healthcare not only during the COVID-19 pandemic but in its aftermath as well.

Conflict of interest

The authors have no conflicts of interest to report.

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