



True Resilience: A Look Inside COVID's Effect on Children with Medical Complexity and Their Families

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Abstract

Purpose of Review Vulnerable children with medical complexity are silent victims of the COVID-19 pandemic, impacted by lack of resources and sick caregivers. In this article, we examine ways in which the pandemic has increased the significant difficulties already experienced by these patients and their families. Increased awareness will lead to improvement in the disparities experienced by this population and improve the ability of healthcare providers to care for them.

Recent Findings The number of children living with medical complexity is rapidly increasing. They face unique circumstances which can lead to compromise in care. This population is especially at risk for complications related to COVID, so may have a more prolonged admission with more morbidities. Children of ethnic minorities are also more impacted by severe illness and death. Finally, access to palliative care has been limited, which is a huge part in caring for these children who have life-long medical care needs.

Summary Children with medical complexity have unique circumstances and the entirety of the effect of the coronavirus pandemic on this group is unknown. While the medical world has found ways to adapt, these changes can increase disparities for this population. Given the increase in number of children with medical complexity living in the USA, it is important to continue to consider the unique challenges they face in the current pandemic and improve the care delivery for both the child and his or her family.

Keywords Children with medical complexity · Technology dependence · COVID-19

Introduction

In November 2019 in Wuhan, Hubei Providence, China, the first person was infected with Coronavirus-2 (SARS-COV-2). Transmission spread rapidly and now it is a global pandemic with over 140 million cases world-wide [1]. Studies have shown that the overall medical impact or burden of the coronavirus on pediatric patients to be less than that of on adults and vary from mild respiratory or gastrointestinal illness to severe multisystem inflammatory response [2•]. However, no study has yet examined the entirety of the impact on a unique group of children: those with medical complexity.

Traditionally, The Maternal and Child Health Bureau have defined Children and Youth with Special Health Care Needs (CYSHCN) as “Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” [3] Children specifically with the most intense and unique medical needs represent a subset of this population and may include those with congenital or genetic abnormalities, significant prematurity with subsequent complications such as chronic respiratory failure, or children with a current or previous hematologic malignancy, just to name a few examples. Regardless of the condition, these children require significant care coordination, possible reliance on technology such as tracheostomy or enteral feeding tube, and polypharmacy to survive. Collectively, this unique group of children has been referred to as “children with medical complexity” by Cohen et al. and this definition will continue to be used in this article [4]. Due to medical advances in caring for these children, over the past 50 years there has

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been a > 400% increase in children with a health condition interfering with daily life [5]. Today, nearly one in four US families has a child with medical complexity living in the home [6]. As a result, there is also a rising rate of complications and childhood disability, with subsequent increases in intensive medical technology use, medical and nursing care, and coordination of needs [4]. Unfortunately, there continues to be a significant degree of unmet need affecting these children and their families [7]. At baseline, significant disparities exist for these families and the current coronavirus pandemic has further widened this disparity. The purpose of this review is to begin to examine how the current pandemic has challenged these families and the healthcare workers who care for them.

Effect of the Pandemic on Children with Medical Complexity and Their Families While at Home

Increased Caregiver Stress and its Effect on Mental Health

One of the most recognizable areas in which these children and their families have been affected by the coronavirus pandemic is regarding increased caregiver stress and its detrimental effect on caregiver mental health. At baseline, 10–20% of parents of medically complex children meet criteria for post-traumatic stress disorder and 40% meet partial criteria [8•]. Specifically regarding children requiring home ventilation, levels of anxiety and depression in caregivers during the pandemic were found to be 38.1% and 42.8%, respectively. One triggering factor is the increased degree of social isolation. Decreased ability to meet other families with similar challenges and decreased availability of psychologists who are specifically trained to work with children with medical complexity and their families also contributes to this sense of isolation and increased levels of depression and anxiety. Some caregivers even perceive their own quality of life to be below that of their child. Improved well-being for the caregiver can have a positive impact on their ability to cope with daily challenges of caring for a child with medical complexity [9••].

Social and Economic Effects on Families

At baseline significant financial and socioeconomic challenges exist for these families and the social and economic impact of COVID has significantly increased these difficulties. Regardless of the amount of support provided, caregivers of children with medical complexity are often forced to stop working to help provide bedside care at home for their children [9••]. Over 50% of parents reported having

to decrease their hours or change to part time and over 20% reported having to stop working or take early retirement to help take care of their child [10•]. Additionally, over 50% of families reported financial difficulties related to providing care for a child with medical complexity [11]. These families are more likely to experience housing instability as defined by a family being behind in payments, a history of homelessness, and a history of multiple moves [12•]. Finally, families with low-income and a child with medical complexity are more likely to suffer from food insecurity as well [13]. During the pandemic, the rate of US families affected by job losses, housing instability, and food security dramatically increased and those households with children have been disproportionately affected [14•]. Kerry Breen offered an invaluable look inside the homes of three children with medical fragility and the effects of COVID on these families. One mother described no longer receiving the correct ventilator circuits for her daughter as they were being distributed to local ICUs supporting patients with COVID. Alternate circuits are not always tolerated and can lead to respiratory distress or failure. Continued direct interface is needed with families of children with medical complexity to improve recognition of the challenges encountered this unique population [15••]. The cumulative effect of COVID on families with children in general and the more specific ramifications on children with medical needs is difficult to quantify. This demonstrates the need for improved awareness of the specific needs of this population as lack of access to what is seen as a basic need—stable housing or utilities can result in significant mortality.

Limited Resource Availability and Increased Risk of Exposure

As highlighted in Breen's article, there are multiple contributing factors to the above-mentioned increased caregiver stress and socioeconomic challenges exhibited during the current pandemic. This may also include decreased access to personal protective equipment (PPE), more limitations on services and therapies for children, and decreased availability of already limited home nursing. However, access to these resources can increase the risk of a caregiver or child becoming infected with COVID. An example would be home health nurse for a child on a ventilator may also split time at a long-term care facility for adults. In addition, concerns regarding increased exposure of children in long-term care facilities may force families to bring him or her home when not fully able to support the child [16••]. More research is needed on the effect of lack of resource availability and parental and/or nursing exposure to COVID on admissions of these children to the hospital or care facility for either respite care or because the child has become acutely ill with COVID.

Effect of Telehealth

The utilization of telehealth has increased during the current pandemic and has been helpful in allowing families to communicate with and be seen by providers without the risk of being exposed to COVID in the doctors' office. Despite the advantages of telemedicine, multiple sites have reported an increase in disparities for patients with medical complexity. This can include not having access to the necessary supplies to participate in telemedicine (stable internet service, a working smart phone or computer, ability to read and use technology), and needing to be evaluated by specialists who must do an in-person exam or intervention as part of his or her evaluation, such as an otolaryngologist in a patient with a tracheostomy. Continued efforts are needed to minimize these differences in care delivery [16••].

Transportation Barriers

While many studies have looked at the effect of the pandemic on disparities related to transportation and its effect on access to healthcare for certain patient populations, few have examined the effect on children with medical complexity. Transporting a child with medical complexity is a challenging task, and it is essential that all children have access to the appropriate equipment for transit and families have the appropriate education on its use. In addition to using a standard car seat or restraint system (depending on the child's weight), some children require additional modifications to be transported safely. For example, children with airway obstruction may need additional neck supports such as a rolled towel, a child with a tracheostomy may require adjustments to traditional straps and harnesses on the car seat, and some children may even require prone positioning in the vehicle. Some children with scoliosis and diagnoses such as spina bifida or cerebral palsy may even require a fully customized seat and require frequent modifications as he or she grows. It is important to note that many children with medical complexity have multiple issues—tracheostomy, abnormal tone, gastrostomy tube, all which require consideration to determine the best method of transporting a child. In addition to transporting the child, his or her equipment must also be transported. Finally, some children may not even be able to ride in a private vehicle and ambulance transport with emergency medical service (EMS) personnel may be required [17•].

Studies have shown that ride share services (such as Lyft and Uber) and public transit cuts have affected residents of lower income neighborhoods to a greater degree than others, essentially worsening already existing difficulties in accessing reliable transportation. As mentioned, telehealth (and mobile clinics in some cases) have been increasingly utilized to help with improving the access to care for all patients, not

all medical visits are amendable to a telehealth visit and the requirements for patients to engage in telemedicine (reliable internet, a working phone or computer) can create barriers [18•]. Regarding children with medical complexities, in addition to medical appointments, important elements of their care may also include as follows: therapy appointments, equipment fitting (hearing aids, wheelchairs, orthotics), visits to the Women, Infant, and Children (WIC) and Social Security offices, and trips to the pharmacy. Given the challenges of transporting a child with medical complexity and the decreased availability of reliable transportation in the current pandemic, there is a huge opportunity for improving access to care for these children by addressing these barriers.

Effect of the Pandemic on Children with Medical Complexity and Their Families While Inpatient

Effect of Inpatient Care Delivery

Previous studies have shown that nearly 25% of pediatric hospitalization days are associated with children with medical complexities [19] with more recent studies citing numbers up to 80% [20]. For many of these children, hospitalizations last weeks to months. Many children have never been home after spending their first months in the Neonatal Intensive Care Unit (NICU). This presents multiple strains on the family—emotional, financial, and psychological. As mentioned previously, children who are cared for at home also have significant challenges they face.

Specific to hospitalized children, increased restriction on visitors and suspension of family-centered in-person rounds have affected these children and their families. COVID has also changed the face of rounds on the inpatient unit—in the complex care setting this involves a carefully orchestrated multidisciplinary team participating in the care of the patient. The goal is to see the child as a whole and not just a diagnosis and each team member is able to offer a key insight to the child's health and well-being. Most important in this group, however, is the child and his or her family. Participation in the decision-making is key to what we refer to as family-centered rounds and leads to improved family satisfaction and outcomes for the children [21]. With COVID, in-person family-centered rounds have been transformed to “virtual rounds” which is rapidly evolving, but difficult to replace in-person rounds.

Populations at Increased Risk of Complications if Infected with COVID

The increased susceptibility of these children to COVID an additional stressor on the caregivers. Previous studies have shown that the course of COVID in children to overall be

less severe with better outcomes than that of adults. However, of the children in this study who were hospitalized in the PICU (Pediatric Intensive Care Unit) due to complications of COVID, 80% had previous medical issues, with the most common being dependence on technology, such as a tracheostomy and ventilator. Other cited comorbidities included congenital heart disease, sickle cell anemia, hematologic malignancies, just to name a few [2•]. As mentioned in the previous section, fear of the increased risk of complications from COVID in this special population can push a family to transition a child home prior to being too quickly and COVID infection in a home nurse or guardian can force a child to be readmitted to the hospital from home, only to get infected with COVID while inpatient [16••].

Populations at risk do not exist in isolation. Like adults, ethnic minorities (specifically Black and Latino children) are more likely to experience severe illness or death due to COVID. They currently represent 65% of deaths. Socio-economic risk factors are similar to children with medical complexity, and they are most at risk without even leaving home. Often, they live at home with multiple extended family members who may support the family financially or be a trained care giver for a child with medical needs. He or she may also be essential workers and risk frequent exposure to COVID for work. Many families may also be unable to access adequate and reliable healthcare. A COVID diagnosis in this household may lead to loss of household, loss of a caregiver, or a significant outbreak in the home. As mentioned, these populations at risk do not exist in isolation and the data does not take into effect the cumulative effect of multiple risk factors—such as being a minority and a child with medical complexity [22•].

Effect of COVID on Discharge Planning and Caregiver Training

The emergence of COVID has significantly affected discharge planning. Difficulty in discharging a child with medical complexity is not an infrequent occurrence, with commonly cited causes including lack of home nursing, presence of tracheostomy tube, family being new to technology dependence, and age less than two years. Children who were newly technology dependent had delays of 26.5 days with over 90% of these days being due to lack of home nursing [23•]. Prior to discharge, a child and his or her family must achieve several milestones. The first is medical stability with minimal to no changes for a time set by the medical team, including being able to tolerate feeds and stable respiratory support. The child should have a pediatrician to follow him or her in the community, one who understands the medical complexity of the child and is willing to take on the care coordination. The patient may also require the clearance of subspecialists prior to discharge, and careful

care coordination to ensure the follow-up appointments are scheduled and the family is able to take the child to the appointments. In addition, the family must have a stable home to support the child, with no anticipated disruption in power, electric or water source, and a home accessible for the child's equipment including wheelchair and crib or bed. Parents must also complete a certain amount of bedside training and formal classes and demonstrate that they are able to care for the medically complex child at home in the event of an emergency or absence of nursing. This often includes formal sessions in which parents or caregivers “room in” and perform all care of the child without bedside nursing support for a time set by the institution. As previously mentioned, many children, especially those with tracheostomies and ventilators, qualify for and require private duty nursing at home [24].

The current strains on parents during the COVID pandemic have made discharge planning and caregiver training increasingly challenging. While some families can find a way to make this work it has presented a huge barrier to discharging a child with medical complexity, a task that by itself is feat. While the effort to discharge the child is carefully orchestrated and well-thought out, readmission is a common occurrence. Studies have found this to mostly be due to medical setbacks for the child [23•] but, as previously mentioned, we are also seeing a significant number of readmissions secondary to loss of home nursing and caregivers becoming ill with COVID-like illnesses, in addition to loss of stable housing. More research on the incidence of readmission secondary to caregivers or nurses becoming ill with COVID and/or loss of resources is needed.

Providing Palliative Care During COVID

Finally, it is important to discuss the impact on the delivery of care to this special group of children, particularly palliative care. Children with medical complexity are at an increased risk of morbidity and mortality during his or her lifetime. These children, their families, and the medical personnel who care for them have greatly benefitted from the expansion of pediatric palliative care in recent years. Integration of palliative care has found to be beneficial and improve the quality of life and well-being of both the patient and family. It can be provided in different ways—either through primary palliative care by the patient's primary care provider (PCP) or through consultation with a pediatric palliative care specialist. Unfortunately, the demand has outpaced the supply and many children do not have access to quality palliative care. Four areas in which palliative care addresses patient care include as follows: symptom management, psychosocial support, care coordination and accessibility, and communication. Each child with medical complexity has a diverse set of symptoms that he or she experiences related to

his or her condition. Examples include feeding intolerance and reflux, pain and spasticity, and secretion management. Having a provider who can adequately address each symptom and the sequelae related to each medication prescribed to manage the symptoms, is critical to the care and well-being of child with medical complexity. The family often requires additional support, and a palliative care team can provide this. Adequately providing care for the family can improve their ability to care for the child. This may come in the form of identifying concerns for depression or anxiety in caregivers, providing support based on the family's spiritual values, and supporting families through especially difficult times such as acute illness, change in baseline condition, or end of life [25•]. Fragmented care often contributes to increased unmet need for these children [26] and creates further burden for the family. Therefore, palliative care teams often take on the role of care coordination including communicating care plans with all specialists caring for the child and helping to navigate a difficult health care system, often with multiple subspecialists. Finally, palliative care teams excel at communication, and this is a cornerstone of the care they can provide. This includes assessing the family and patient's understanding of the medical condition and prognosis, discussing, and creating the care plans to be shared with the subspecialists, participating in shared decision-making with the family, and advanced care planning. Having access to palliative care, both at home and in the hospital, and the services the team can provide is crucial in the care of the entire family [27•].

Palliative care teams and their services have been uniquely affected during the current coronavirus pandemic. One of the most noted changes was related to team cohesion during the pandemic. In one study, over 60% of palliative care team members surveyed reported the team dynamic felt more “distant” during the pandemic. This was found to correlate with the increased push from hospitals to have some team members working from home and others working on site. Respondents reported increased challenges in communicating with each other regarding patient care matters and supporting each other given the emotional demands of the job. As previously mentioned, multidisciplinary rounds mostly have transitioned to a virtual platform for palliative care teams and there was a decrease in the percentage of teams who communicated multiple times per day regarding patient care. Visitor restrictions also have impacted palliative care teams as less than 1% of hospitals allow extended family members at the bedside. This has directly affected the support available to the child and his or her caretakers, as well as their interactions with the palliative care teams such as for conversations to discuss goals of care or the transition home. Finally, despite the rapid evolution of telehealth, nearly three-quarters of providers felt the care provided virtually was not equivalent to in-person care. Therefore,

despite the known positive impact of palliative care teams on families, many providers feel their work has been significantly affected by the coronavirus pandemic, mostly due to a decrease in ability to perform in-person care [28•].

Conclusion

This review article discussed several ways in which COVID has affected the care of children with medical complexity including increased burden on an already stressed caregiver, more difficulty with discharge of these patients while inpatient, increased challenges in securing resources to help provide reliable care for these children, and changes in which palliative care, and medical care in general, is delivered to these patients. Telemedicine is rapidly evolving and has overall improved access to care for these fragile children; however, significant barriers continue to exist in providing care for both the caregivers and the care team. COVID increases already noted health disparities, attention should also be focused on families with children with medical complexity as this is a growing population with increased morbidity and mortality. In addition to further examining the disparities that COVID has created by increasing our reliance on technology and advanced communication, many areas remain unstudied and would perhaps lend well to survey studies with parents of children with complex medical conditions. This may include providing for and keeping a medically complex child safe during COVID with limited resources and end of life planning during COVID. With the development and widespread administration of the COVID vaccine, future studies may look at the percentage of home health care workers who are vaccinated versus those who are employed by hospitals and continue to examine disparities that exist with vaccine allocation. Examining these areas can hopefully improve the ability for families to be able to better connect with providers and care teams, and the whole community, and have needs met; therefore, providing better care for the child with medical complexity and his or her family.

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