COMMENTARY:

PANDEMIC IS DECLARED:

Early Experience from Families of Children with Medical Complexity during SARS-COV-2 Lockdown: Information to Drive System Change

Angeline Hassinger, parent and L.P.N.,[a] Jennifer Lail, M.D., FAAP[b]

ABSTRACT

We describe reports on emergency home management by parents/families of children with medical complexity in the weeks following the declaration of the COVID-19 pandemic as a national emergency on March 13, 2020. Families reported interruption of home care nursing, medication, formula and supply/equipment shortages, and tight infection control restrictions as early challenges. Persistence of the pandemic and "lockdown" for months prompted other concerns about family mental and physical health, postponed education and therapies, deferred preventive care, financial crisis, and insurance and advocacy challenges. Mitigating the risks of these gaps in care required intense family effort. It was complicated by the disrupted access to usual health system support and by the infectious risks incurred by opening the child's home/residential center to outside help. Identification by families of the care gaps and struggles occurring during this pandemic will be important as future emergency and disaster planning and adapted policies and processes appropriately include this specialized and growing population of children. Acknowledging that families managed this crisis with limited help, we detail these challenges through the voice of one family's experience during the pandemic.

---

[a] Parent, Licensed Practical Nurse, Cincinnati OH

[b] Jennifer Lail, LLC, Principal Consultant, Durham, NC; formerly of Cincinnati Children's Hospital Medical Center

INTRODUCTION

The SARS-COV-2 pandemic (COVID-19) and subsequent “lockdown” as a result of the national emergency declared on March 13, 2020 caused disruption in daily life for the entire US population. For US children with medical complexity (CMC) and their families, little has been published about the impact of ensuing quarantines, school and business closures, health system alterations and supply chain interruptions.

The population of US children with medical complexity is growing, constituting as much as six percent of the children insured by Medicaid or the Child Health Insurance Program.[1] Care for these children, who may have multiple chronic conditions, high health care service needs, functional limitations, and/or technology dependence for activities of daily living is often delivered in the home setting by family members, along with friends, home-care nursing services and community support.[2,3,4] CMC may have frequent hospitalizations and are at increased risk for instability or death when faced with infections or breaks in their care patterns. Many families of CMC adapt their homes and lives to provide home care similar to that delivered in the intensive care setting. These children have complex, chronic and often rare conditions. Their families are accustomed to isolation and emergencies and most are skilled at implementing infection control procedures, as seasonal respiratory infections may be life-threatening for their child. A number of these children are not eligible for nursing support in the home, and some are permitted help from aides. The voice and expertise of a wide array of families and caregivers for CMC is critical to the design and implementation of crisis-management solutions. While emergency preparedness is being addressed for this population from the perspective of natural disasters such as fire, power outages, or climatic emergencies, the impact of a global pandemic on this population is unprecedented.[5] Survival for CMC is dependent on medications, medical supplies for ventilation, feeding and daily care, and essential equipment for airway maintenance. Supply chain support for timely availability/delivery of these items and needed personal protective equipment has been affected. Access to health care and trusted, reliable information about the pandemic is critical as these families create new networks of care for their children. Child and family quality of life are impacted deeply when this complex support network is disrupted; the annual winter respiratory infection season will likely amplify the care needs as well as personnel, supply and equipment shortages.

Leaders from Family Voices (FV),[6] a national family-led organization linking family support organizations to families of children and youth with special needs and disabilities, have begun to gather reports from families across the US, listed in Table 1. These anecdotal reports have identified recurrent themes of the challenges of caring for children with complex conditions during the pandemic. Responding to FV themes, the following provides a detailed and personal narrative report from the perspective of a mother/family of a CMC on some of these pandemic challenges and adaptations in the daily home care of their daughter with hypoxic-ischemic encephalopathy, tracheostomy and gastrostomy dependence, seizure disorder

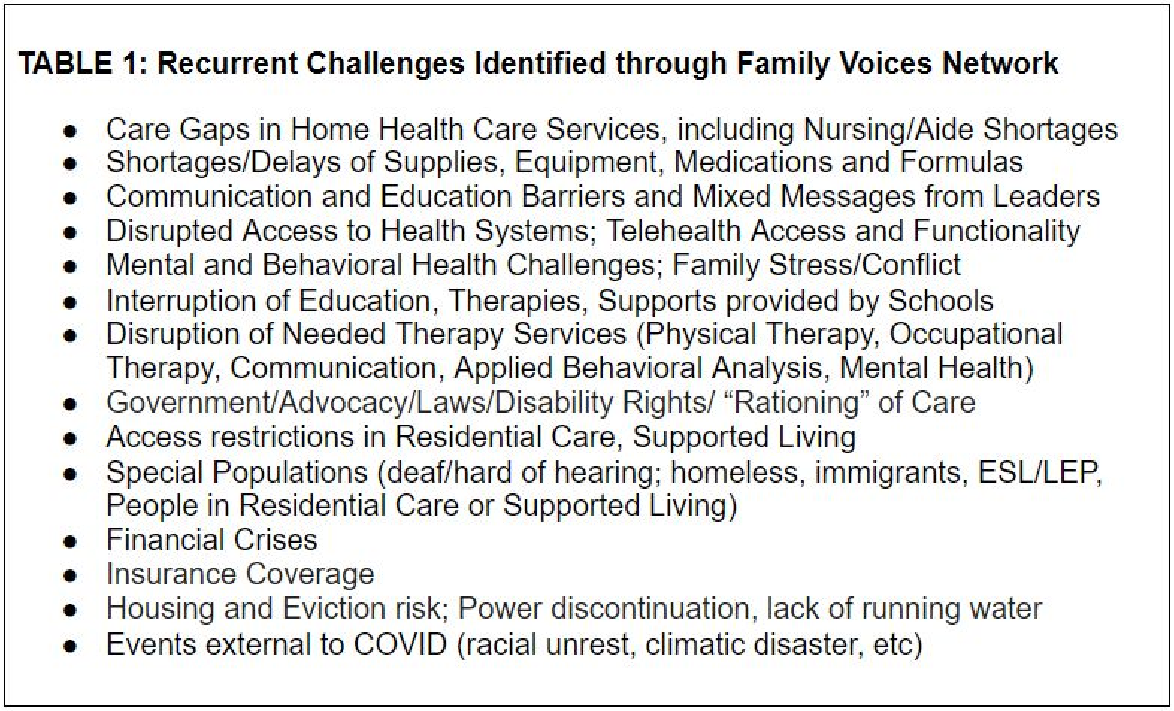

TABLE 1: Recurrent Challenges Identified through Family Voices Network

- Care Gaps in Home Health Care Services, including Nursing/Aide Shortages
- Shortages/Delays of Supplies, Equipment, Medications and Formulas
- Communication and Education Barriers and Mixed Messages from Leaders
- Disrupted Access to Health Systems; Telehealth Access and Functionality
- Mental and Behavioral Health Challenges; Family Stress/Conflict
- Interruption of Education, Therapies, Supports provided by Schools
- Disruption of Needed Therapy Services (Physical Therapy, Occupational Therapy, Communication, Applied Behavioral Analysis, Mental Health)
- Government/Advocacy/Laws/Disability Rights/ “Rationing” of Care
- Access restrictions in Residential Care, Supported Living
- Special Populations (deaf/hard of hearing; homeless, immigrants, ESL/LEP, People in Residential Care or Supported Living)
- Financial Crises
- Insurance Coverage
- Housing and Eviction risk; Power discontinuation, lack of running water
- Events external to COVID (racial unrest, climatic disaster, etc)

and marked spasticity secondary to accidental trauma. Her story has similar features of many children with medical complexity who depend on technologies for survival and echoes the challenges identified through FV. Reports from families have helped inform thethe curriculum for the COVID-19 & CMC ECHO series, a partnership between the Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for CMC, led by Boston University's Center for Innovation in Social Work and Health, and the American Academy of Pediatrics (AAP).[7] Further information is needed from families who faced additional barriers around language, unemployment, literacy, housing, transportation, food insecurity and co-existing disasters such as racial unrest, hurricanes, fires and tornadoes.

A FAMILY STORY

Abigail is a 15.5 year-old female (85 #) with severe brain damage from an accident at age 3. She has a tracheostomy with nighttime O2 administered by trach collar. She is gastrostomy fed, has a fairly well controlled seizure disorder and marked spasticity with bilateral hip dislocation. She requires suctioning and turning every 2-3 hours around the clock. She has a history of recurrent pneumonia prior to her salivary gland ligation. She has not been hospitalized in the year prior to the onset of the COVID-19 pandemic in March 2020. Her family history is unremarkable.

She lives with her biological parents and 2 healthy brothers; the father is an essential worker and the mother is an LPN who provides care for Abigail on evening shifts and home-schools the younger brothers. Prior to the pandemic, Abby attended school hours with a nurse, but the nurse left the position in March 2020, as the pandemic was declared. The mother has reached out to home nursing agencies, initially unable to get a replacement for the nursing hours. Family friction has ensued about rules around infection control measures. The family did not have any extra personal protective equipment (PPE), which complicated the issues of bringing in external help to care for her. Ms. Hassinger describes other challenges below.

Her family lives in a mid-sized city with COVID-19 cases but was not considered a “hot spot”. The writing of this article took place between March and October 2020, prior to the “second wave” of COVID-19 cases.

CHALLENGE: Care Gaps in Home Health Care Services, including Nursing and Aide Shortages

Angeline Hassinger (AH), 5.24.20 “About a week before the schools closed, we lost our day shift nurse. She had only been with us for a couple of weeks. We had hired her because she was willing to go to school with my daughter, and the nurse we had worked with for over a year was not. So, my daughter went to school for about 1.5 weeks this year, before COVID-19. After all the effort it took to get her there, we were extremely disappointed. Now we had no nursing help at all, since I work the overnight and weekend shifts myself. In the beginning, though, I was okay with not having a nurse. I felt like it was one less person who could potentially be a source of infection to her. I thought maybe it was a blessing that things had worked out this way.”

AH, 6.7.20 “We now have a full-time day shift nurse, and I am grateful. But she is also experiencing challenges related to the pandemic and requires grace. I have had to re-evaluate my standards for nurses working in my home and in some ways settle for a lesser quality of care. I feel like "at least my daughter is safe and I can take a break!!" This makes me feel guilty, but I am desperate. Even the respite facility we currently use, St. Joseph's Home, has been closed during the pandemic. Since we lack local family, we truly have no options for respite. I can't imagine how this would be compounded if I didn't have the help of my husband who is willing to occasionally send me to a hotel for a break!”

AH, 9.6.20 “As the pandemic continued on, I became concerned about all of the hours I was working. At first, I didn’t know that not all states allowed parents to be trained/paid to care for chronically ill children. I had worked hard for my LPN license. I went back to school as an adult with a handicapped child while homeschooling my children, because I was unable to work outside my home even at that time due to nursing unreliability. Whenever a nurse called off from work, I would have to call off. As my husband had the better paying job with benefits, I was the primary fallback. But when I learned that parents with the appropriate credentials could get paid for caring for their child, it seemed the obvious choice. Now I worry that since I am working so many hours, Medicaid may decrease my daughter’s nursing coverage hours. She currently receives 2 shifts each day. I bill one to help financially at home, and for the *other, I hire a nurse so I have respite, can complete my chores, and home school the boys. I feel like I could potentially be punished because nursing isn't available."*

"It has become nearly impossible to find a nurse willing to attend school with my daughter. As a result, my daughter no longer attends school, and I am managing her care without outside assistance. When I speak with people about this, they just don't get it. They say things like, "It must be nice to get paid to care for your own kid." They don't really understand what it is like to care for a chronically ill child 24/7 and still complete housework, homeschool, maintain some normalcy for the typical children, and take any time for self-care. But it is a lot of extra work. My daughter requires medications/turning every 2-3 hours. Around the clock. Her shower alone takes at least an hour. She has seizures and needs suctioning. She needs cough assist therapy twice a day (20 minutes each time) and passive range of motion to prevent contractures. She also deserves attention and time. She is 85 pounds and isn't easy to lift or move, especially with her spasticity. She is a teenager and sometimes has an attitude and demands attention."

AH, 10.26.20 "I have spent a lot of time considering how this could be helped in the future, but coming up with practical solutions is very challenging. If a child has hours allotted but there are no nurses to staff them, what can be done to help? If you allow STNA's or unskilled workers to help, the state may see that as a reason to decrease nursing hours saying, "The patient doesn't require this level of care." Could these kids come into the hospital for respite? This way parents would know the caregivers were properly trained and that their child would be safe. In a pandemic, though, the hospital would be the last place many parents would want their child to be, and it doesn't seem to be the proper use of the facility. Maybe if we can't help with the direct issue, we could help indirectly by taking something else off of the caregiver's plate? Could meals be sent or gift cards for take out? Could a cleaning service be provided? I don't know."

System Changes: All States should permit parents to be trained and paid for care-giving without risk to their Medicaid nursing hours, especially when documented nurse/aide shortages create staffing unreliability.[8] Parents have the untenable choice between potential exposure to COVID-19 from outside caregivers, providers who may not be trained for their child's needs, or continuing the care single-handedly. Policies must acknowledge that lack of trained help in the home and school setting also obstructs the CMC's access to education, therapies provided at school, and the ability to participate in social or recreational activities settings. [8,9]

CHALLENGE: Shortages/Delays of Supplies, Equipment, Medications and Formulas

AH, 5.20 "Just before the pandemic began, my insurance company had notified me that we would no longer be able to use the pharmacy that we had used for 12 years. I knew the pharmacist and staff by name. We had learned to anticipate and prevent various problems that came up when filling my daughter's prescriptions, and things were finally working smoothly. For instance, *insurance often refused to fill liquid medications that more typically came in tablet form, because they are more costly. My daughter needed them in liquid form since she has a g-tube and is unable to take medication by mouth. I was shocked to learn that I only had two options for pharmacies, the insurer's mail order pharmacy or another community pharmacy. In addition, we were now required to fill medications for 90 days at a time, which also created difficulty, as some of her compounded medications are only good for 2 weeks at a time. Another issue we faced at the beginning of the pandemic was a shortage of one of her seizure medications, Onfi. There was a manufacturing delay. Each time we needed to refill the medication, the pharmacy team would have to determine which pharmacy had it in stock, and I would drive to pick it up. Regarding supplies and formula, things have gone smoothly. The only inconvenience has been that the supply company is now unable to bring things into the house for delivery, so they leave them outside of the front door. Unfortunately, they cannot generally give a specific delivery time or date, so if we are not at home, formula may be left in the sun, or supplies may be left in the rain until we return home to bring them inside."*

System Changes: The disrupted supply chain for medications, medical equipment and PPE must be adapted to prioritize funding and delivery of these items to this high-risk population during crisis, giving allowance for families to keep a quantified backlog of such life-sustaining supplies. Their complicated and chronic daily medication regimens can be identified in pharmacy and insurance data bases with proactive alerts of shortages to families and providers to pursue medically acceptable alternative medications, without prior authorization. Restrictions on 90-day supplies of controlled substances necessitate contacts with insurers and more frequent pharmacy interactions, increasing PPE utilization. Examples of shortages include Albuterol metered-dose inhalers (while avoiding the possible aerosolization of virus in nebulized delivery) and shortages of attentional medications, which impacted parents and students in at-home and online learning settings.[10] Home care companies, who experienced short supplies of ventilatory equipment, supplies and PPE must confirm protocols and processes to continue reliable provision during emergencies.[11] As families underscore, breaches in the care protocols of CMC increase the risk for clinical instability, health systems utilization and may involve increased exposure to infection, and more PPE utilization. With ICU beds and ventilators in short supply, families fear that judgements about quality of life and related rationing of supports could affect their child.[11]

CHALLENGE: Communication and Education Barriers and Mixed Messages from Leaders

AH, 5.24.20 "When Ohio began to respond to this virus I was completely on board with the recommendations for quarantine. I kept my 12 and 13-year-old sons home from activities even before the state began to shut them down. The challenge was, my husband was not of the same persuasion...he thought it was all an over-reaction. This caused arguing -

understatement - fighting between us. I was genuinely worried about our daughter's health, and he sincerely believed that the precautions were unnecessary. He loves Abigail and didn't believe he was putting her in any danger by his actions. The only rules I could consistently maintain were:

1)My daughter stays home
2)No one can come into our house other than family
3)Basic handwashing"

AH, 9.6.20 "I consider myself a reasonable person and prefer to make decisions based on fact- especially with regard to something like keeping my family healthy in a pandemic. The challenge is, it seems difficult to determine what the facts are. Early on, this was completely understandable. People in leadership roles had to make decisions based on limited information and worst-case scenarios. This old adage, "Better safe than sorry," seemed to apply. Leaders made decisions based on data regarding what was happening in other countries and didn't know if the data they were receiving was even accurate, in some cases. In the beginning, we lacked access to reliable tests to determine who was infected. This was a big problem, because in many people COVID symptoms could look very similar to the common cold virus but could be lethal for those more susceptible to the virus, like my daughter. When testing became more available, more concerns arose that caused my trust in the reliability of the reported number of infections to waver. Sometimes having all of this information at our fingertips on the Internet is a blessing and a curse."

AH, 9.18.20 "As the pandemic dragged on, we were anxious to return to life as normal, so hearing that things were possibly not as bad as they seemed encouraged us that it may be safe to loosen up on some of our restrictions. Take masks, for example. In the beginning when they were "highly encouraged but optional", my teenage boys flat out refused. Now that they are mandatory, I am using it as a lesson in obeying authority. You don't have a choice on whether or not you wear the mask when entering an indoor public facility. You have a choice of whether or not you enter Walmart, or a restaurant, but not about putting on a mask. Now they pretty much do it without grumbling. And I don't think they are overly irritated in wearing them. So, it seems that it was more an issue of attitude than mask-related discomfort."

AH, 10.18.20 "I don't really feel like there is anyone I can trust in making these decisions right now. My daughter had a primary care provider that I trusted for many years, but she recently retired. This provider managed most of her care, so the need to see other providers was considerably decreased. Building trust takes time."

System Changes: Governing bodies must unify their health messages with the scientific community, delivering transparent, consistent information and acknowledging when answers are unknown, evolving or still being researched. Since access to information depends on television, internet availability, phone service and literacy/language proficiency, health information must be delivered and repeated through an array of modalities. Support is needed from all health system components such as health care providers, pharmacies, public health, home health and community health workers. Shared decision-making with trusted providers can customize recommendations to a family's personal risk tolerance and clinical situation and promote accurate information-sharing. An uncoordinated National effort has left families to decide their own appropriate responses at home, school and in their health care system.

CHALLENGE: Disrupted Access to Health-Systems; Telehealth Access and Functionality

AH, 5.24.20 "Regarding medical appointments, I am trying to avoid hospitals and doctors' offices. It seems to me that these would be the most likely places to contract COVID-19. I contacted all of my daughter's physicians via MyChart and asked them to put in lab orders so they could be completed in one visit. I insisted on her visits being conducted over tele-health whenever possible. I am even holding off on well child visits for my other children for now."

AH, 10.18.20 "I am beginning to feel more comfortable with in person healthcare. Seeing the downward trend in the number of cases is encouraging. I am also reassured to see more agreement from the experts regarding how COVID-19 is spread. This helps me to feel like the safeguards hospitals and physicians offices are putting into place could be effective. It is also beneficial when policies are clearly posted and explained. I need to know that people are taking this seriously. Abigail usually has an outpatient surgery each year to look inside of her tracheostomy and lungs, since she struggles with recurrent pneumonia. I was hesitant to schedule this procedure this year. We only just consented to move forward with the procedure this month. I am glad we did so. She has grown, and it was necessary to make some changes to her tracheostomy tube size, which we may not have known if we hadn't completed the procedure."

System Changes: Families report avoiding accessing health care unless the interaction is critical. Routine, preventive and chronic condition care is being postponed and/or missed, including vaccines.[12,13] Needed, but elective surgeries have been postponed.[12] Rapid rise in Telehealth usage and payment for such services has been positive, but an estimated 14 million Americans lack internet service,[14,15] equipment or experience to access telemedicine, particularly in rural areas. Policies, best practices and payment for Telemedicine must be codified. Pediatric and medical practices will need ongoing guidance around adapting care practices for infection control, using population health management to find and remediate care gaps during the pandemic and support to restore in-person care for wellness visits as well as acute and chronic care. Strategies to sustain staffing and restore revenue to practices are critical to maintain the pediatric workforce.

CHALLENGE: Mental/Behavioral Health Stability and Family Stress and Conflict

AH, 5.24.20 "My husband's work was considered essential. He has not missed a day since all of this began. While on the *positive we had no loss in income, I had no help at home, and no respite. I no longer felt this was a blessing. My boys, now 12 and 13, had no option of continuing their activities, since everything was closed for quarantine. Each day seemed to bring more loss. No camp. No ninja class. No working at the farm. My 13 year- old believed that all of this was unnecessary, and he wanted to rebel, continue meeting with friends, and ignore government mandates. This caused increased stress between the two of us. My younger son was more compliant. He was disappointed but agreed that the changes we were experiencing were necessary.*

"At this point I am billing 112 nursing hours a week. Sure, I am putting away some extra money. But I am tired. I rarely get a break, because if I am home, I see everything that needs done, and am unable to rest. But I can't really go anywhere to get out. I have reached out to my agency a few times to remind them that I prefer hiring a day shift nurse to working the hours myself. They say they don't have anyone at this time. I worry that we may lose nursing hours if Medicaid waiver sees that I am working all of them. But I don't want all of them! This also causes anxiety."

AH, 5.24.20 "I don't really feel like our situation has changed with us being essential workers since I have been blessed to be a stay-at-home mom, except I am not getting any respite, as previously mentioned. Also, we don't have family support, as our families live more than 12 hours away. I can't imagine how this would be compounded for a single parent family that can no longer send their children to school or daycare. It is difficult to be supportive of family members when you are drained yourself. Typical supports—like friends and family—are also strained, so it is hard to rely on them. This creates a guilt cycle. It goes something like this... "Parent loses temper on teenage son. Angry words are exchanged, feelings are hurt. Parents feel guilty and beat themselves up, considering themselves a bad parent, a failure. Which depletes needed emotional energy. Cycle repeats with increasing frequency."

AH, 5.24.20 "During full quarantine, time spent on computers and cell phones dramatically increased for my teenage boys. They played and talked with their friends over the computer, which seemed like a good way for them to socialize...but it was all they wanted to do. We struggled to come up with other ways for them to spend time together. We had game nights with friends over Zoom. I brought in new games for family time, puzzles, and we baked fun treats based on the Nailed It show. My 13 year- old wasn't really happy with any of my efforts. He just wasn't happy.

Eventually, I allowed the boys to start spending time outdoors with a few of the neighborhood kids. They did a lot of biking together, and were earning new freedoms. This seemed to really improve my 13 year-old's mindset. It also gave me some moments of quiet in my day. Now we are increasing our circle a little bit. I am allowing the boys to spend time with a couple of their best friends. They come into our house and we go into theirs. But each of our families is still keeping a distance from others. I have called this chapter of my life "creating a tribe."

System Changes: Attention to the ongoing mental and behavioral health repercussions of the pandemic on the CMC's entire extended family will necessarily be part of the restoration of care, including inquiring about and addressing the family's concerns and stressors. With anxiety escalating in the setting of COVID-19 infection or exposure in the home, the early identification and training of back-up caregivers should be part of emergency planning. Families report feeling trapped between meeting the child's needs and managing their own self- care and that of the entire family.[16] Siblings, also affected by the diversion of attention from their needs, will need specific focus on their fears and frustrations. Families describe the struggle of a delicate balance of risk between the infection protection and isolation of the CMC and the mental health and quality of life of the family; siblings often have lived the risk of hospitalization or death when their sibling becomes sick. Strategies and funding to provide safe, reliable respite care for families of CMC will be essential.

CHALLENGE: Interruption of Education, Therapies, Supports provided by Schools; Disruption of Needed Therapy Services (Physical Therapy, Occupational Therapy, Communication, Applied Behavioral Analysis, Mental Health)

AH, 5.20 "Regarding returning to school, I don't think I would send Abby right away even if it was an option. However, after watching the world open up for a period of time and tracking the number of cases, I may consider it."

AH, 10.18.20 "While Abigail may express herself differently than most children, she can communicate. We learned how to use communication devices with the help of therapists at her school. These therapists taught us how to help her interact with her world. This requires a lot of trial and error. It would be very expensive for me to purchase these devices as an individual and try them until I found one that worked, but school has them readily available. School is also crucial in meeting socialization needs for her. When the schools closed at the beginning of the pandemic, we noticed that Abigail would sleep most of the day. When we were able to send her back to school this year, she has generally been awake and alert when she gets on the bus, and stays awake until she is home. School also acts as a one stop shop for adjusting equipment such as hand or foot braces and her wheelchair. This decreases the need to travel to other specialists, and allows them more time to observe and tweak any changes they make to the equipment to make sure it is a good fit for Abigail."

System Changes: The pandemic has highlighted the critical role of the school system in the health of all children, providing meals, exercise and trained adult supervision as well as education. For CMC, the role of schools as sustainers of learning, socialization, daily functional skills and a parent's ability to work needs recognition and funding. Schools often hold the key to augmented communication, applied behavioral analysis services, and access to equipment such as standers. Abrupt halts to physical, occupational, communication and behavioral therapies can cause regression in habilitative progress, decreasing capacity for activities of daily living. Having a child in a safe school setting also permits parental attention to other siblings' needs as well as brief respite for parents/caregivers and therapies for the CMC.[17] To permit a safe return to school, school systems must be adapted and funded for trained staffing, PPE, cleaning protocols, including the procedures and medications required by CMC. For a safe return, children must be included in the COVID-19 vaccine safety and efficacy research, with CMC being identified as a high risk group in the prioritization of vaccine distribution.

CHALLENGE: Government/Advocacy/Laws/Disability Rights/“Rationing” of Care

AH, 9.6.20 “It is scary when you consider limited resources, when you have a handicapped child, you feel like they may not be chosen over a typically healthy child if a choice had to be made. I think of the movie Pearl Harbor. Immediately after the bombing injured people are everywhere, and there aren't enough nurses or supplies to treat everyone. They enter into an emergency triage situation. People are forced to make impossible decisions. Who should we treat? Probably those most likely to survive and live with a high quality of life. If my daughter had gone to the Emergency Room at the height of the pandemic, and had required a ventilator to survive, I wonder if they would have chosen to save someone they deemed to have a higher chance of surviving or a higher quality of life than her. To take this a step further, I fear that someday the government may make decisions about treatment for individuals like my daughter. What if they decide people like her are a drain on the system and refuse to provide coverage for her care?”

AH, 9.3.20 “At this point, as the pandemic stretches on, I find myself striving to find a balance that will allow the needs of each family member to be met. Lockdown measures employed at the onset of the crisis are not sustainable in the long term. I am constantly doing a cost benefit analysis regarding things like going to the doctor, sending Abigail to school, and allowing my healthy, typical teenage boys to visit with friends. We tried to look at the pandemic from a positive perspective as a chance to take a step back and become less busy. As things have slowly begun to re-open, we have carefully evaluated which are worth adding back in. We feel that we have a healthy connection with our children and that we enjoy each other and communicate well about the hard stuff. But I can't imagine how much more difficult this could be for families that are already very emotionally strained.”

System Changes: Families of CMC must be informed of opportunities for support, such as Home and Community Based Services, as early as possible in the evolution of their child's diagnosis, [18] as these programs may have lengthy wait lists. Rapid, albeit temporary, policy changes offer hope to our families of CMC and need to be codified. CMS temporarily waived some policies on telehealth and telemedicine, permitting audio and video interactions and permitting cross-state line interactions.[19, 20] Specific to CMC, some states have increased eligibility for home and community-based services (under a Section 1135 waiver) and afforded temporary flexibility in HIPAA laws and prior authorizations.[20,21] The Office of Civil Rights and Health and Human Services underscored federal civil rights laws against disability discrimination, requiring those with intellectual disabilities or communication barriers necessary accommodations, including the ability to have a family member present during health care. [22] State-wide variation exists on the availability of paid family leave to care for a chronically ill child.[23] Efforts around dissemination of this information to families and health care providers must consider literacy, language and communication barriers while parents deliver 24/7 care in isolation.[24] Parents will need definitive policies and reassurance about fears of health care rationing, their ability to be with their child/youth in emergency and inpatient settings and the possibility of implicit or explicit judgement about their child/youth's quality of life, regardless of where they may seek care.

DISCUSSION

This family's generosity with describing their lived experience highlights the recurrent and emerging concerns families report around their pandemic-related challenges to caring for their child(ren). The natural history of COVID-19 disease in CMC is unfolding; early data on hospitalization of children with this infection underscores the increased risk of those children with chronic conditions.[24] Even though children appear to be less severely affected clinically than adults by COVID-19 infection,[25] the indirect impacts such as delays in needed health care, anxiety, social isolation, interruption of education, therapies, socialization and poverty related to job losses are powerful and will continue to affect families and children.[26] Traditional US health care addresses illness and disease, and has been less focused on these indirect yet equally profound repercussions.

A diverse array of families and caregivers of CMC must inform the evolving research, policies and processes to enable more relevant work toward timely solutions to the many challenges faced by the population of CMC. Along with families, a child's functional community members (ex: teachers, friends, therapists, medical equipment suppliers) should be included in the planning, design and implementation of strategies, as the role of the healthcare system can only be part of necessary solutions. With their unique needs, the expanding population of CMC must be identified and managed as a high-risk group, with specific emergency planning focused on sustaining their essential care. Clinical registries of this population can assist with emergency preparedness, pro-active outreach to address needs and the ability to identify and restore missed care.

Families and children need to "belong" to a supportive health community as exemplified in the Medical Home model, to problem-solve, meet needs and make decisions. Proactive processes to assure emergency access to familiar health systems and providers can remove a barrier. Since a timely medical product supply chain is essential for survival, comfort and quality of life, we must identify and remediate pandemic-related system failures for future crisis management. To prevent regression in skills, innovative community-based therapies and collaboration with school systems for education, adaptive equipment and necessary therapies should be developed and funded. The mental and emotional well-being of families and caregivers must be prioritized and services funded to sustain the intensity required to adapt to and care for our CMC in the setting of long-term isolation, stress and fear. Unique to this population are concerns about disability rights, the ability of parents to serve as paid care-providers, and concerns about potential rationing of care or life-saving equipment. Families report their medical challenges are complicated by behavioral and mental health concerns, and/or by learning or developmental disabilities. With the larger population, they share the financial threats, potential employment, and insurance and transportation challenges. A subset of our CMC have amplified challenges as they face food and housing insecurity, unemployment, multi-generational living, language and literacy barriers and regional events such as hurricanes, fires and racial unrest. These families' insights provide critical information to be gleaned as we work to improve systems of care for CMC.

Perhaps one of the most critical shortages for CMC has been pediatric-trained, reliable home health nurses and aides to assist families and avoid hospitalizations. Efforts are being made to train more pediatric home care nurses, but equitable payment and employment benefits for such work is essential to enhance that work force.[27] States that have successfully built systems to pay trained family members for at-home caregiving can share their processes, fee schedules and training criteria with other states. All employers should assure paid coverage for worker illness to prevent propagation of exposures; too, clear standards on paid family leave for emergencies are needed.

The continuation and expansion of telehealth necessitates equipment, internet access and training on the use of telehealth and telemedicine. Guidelines for what is appropriate for telemedicine vs. what requires in-person care must be developed, with appropriate malpractice coverage for virtual care. As telehealth expands, continued support for and access to the Medical Home[28,29,30] model of care should be a priority, building trusted, informed relationships and using team-based care in healthcare settings. In the Medical Home setting, explicit emergency care planning with regularly scheduled updates are important and should include a contingency plan for trained back-up caregivers and strategies for protracted emergency situations.

Even pre-pandemic, there is ongoing need for respite care for family caregivers, with endorsement in policies and interventions of the high risks for physical and mental health challenges these families face.[17] Special populations with heightened challenges such as immune compromise, communication disorders, or mental health/behavioral disorders will need specific attention, as will those whose social determinants of health compound their medical complexity dramatically. It will be important to pair both translational and bench research to inform timely policy making, possibly in alliance with other high needs populations such as geriatrics.

Quality improvement initiatives to implement recommendations efficiently and decision support tools in health care for CMC can support emergency planning, caregiver training and improved access to health systems.

CONCLUSION

In the growing population of children with medical complexity, the COVID-19 pandemic prompted unique challenges, handled predominantly by the child’s family, “behind closed doors”. It also exposed long-standing gaps in care that individual families have endured, which were often invisible to the wider world. To contribute to the emerging scientific foundation on COVID, we must incorporate families’ narratives of their obstacles and barriers in their child’s 24/7 care--both those anticipated and ones never expected. Deliberate efforts to solicit and capture these rich insights while they are recent memories will inform much needed solutions to address the barriers and obstacles specific to this population. For a child who depends on technology or medications for health and survival, whose care is fortified by school services, therapists, home nursing and aides and home care suppliers, there has been no emergency care plan or road map for daily management during a global pandemic. More research is needed, including a wider clinical and demographic sampling of family input to guide the funding, emergency preparedness, disability rights advocacy, and advanced planning for our children with medical complexity.

DISCLOSURES/CONFLICTS OF INTEREST: None

CORRESPONDENCE: jenniferlailllc@gmail.com

TO CITE: HASSINGER A, LAIL J. PANDEMIC IS DECLARED: Early Experience from Families of Children with Medical Complexity during SARS-COV-2 Lockdown: Information to Drive System Change. Complex Care Journal. 2021; 2.

REFERENCES

1. Bergman D, Keller D, Kuo D, et al. Costs and Use for Children with Medical Complexity in a Care Management Program. *Pediatrics.* April 2020, 145 (4) e20192401; DOI:https://doi.org/10.1542/peds.2019-2401
2. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Millwood). 2014;**33**(12):2199–2206pmid:25489039
3. Foster CC, Agrawal R, Davis, M. Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, and Future Directions doi: 10.1377/hlthaff.2018.05531 HEALTH AFFAIRS 38, NO. 6 (2019): 987–993
4. Kirscher, K, Iezzoni, L, Shah, Tanya. "The Invisible COVID Workforce: Direct Care Workers for Those with Disabilities" *To the Point, Commonwealth Fund*, May 21, 2020. https://doi.org/10.26099/5x3b-fq66
5. Center for Disease Control. Caring for Children in Disasters: Health Professionals https://www.cdc.gov/childrenindisasters/professionals.html
6. Family Voices. https://familyvoices.org/
7. Center for Innovation In Social Work and Health, Boston University School of Social Work https://ciswh.org/ciswh-project-to-address-covid-19-and-care-of-children-with-medical-complexity; CMC Collaborative Improvement and Innovation Network (CMC CoIIN) https://ciswh.org/project/CoIIN-CMC
8. Foster CC, Shortage of home care personnel highlights the need to strengthen policies, research, systems of care. AAP News https://www.aappublications.org/news/2019/12/10/focus121019 December 10, 2019)
9. Personal Care Aides "50-State PCA Training Project" provided by the Center for Personal Assistance Services at the University of California, San Francisco (National Institute on Disability and Rehabilitation Research, Grant No. H133B080002), the Centers on Medicare and Medicaid Services, The SCAN Foundation, and the Ford Foundation. https://phinational.org/wp-content/uploads/legacy/research-report/pca-training-reqs-state-findings.pdf)
10. Drug Shortages: https://www.accessdata.fda.gov/scripts/drugshortages/default.cfm
11. Ranney M, Griffeth V, Jha Ashish. Critical Supply Shortages — The Need for Ventilators and Personal Protective Equipment during the Covid-19 Pandemic. *N Engl J Med* 2020; 382:e41 DOI: 10.1056/NEJMp2006141
12. Framework for Healthcare Systems Providing Non-COVID-19 Clinical Care During the COVID-19 Pandemic. https://www.cdc.gov/coronavirus/2019-ncov/hcp/framework-non-COVID-care.html
13. AAP: CriticalUpdates on COVID-19: "Caring for Children and Youth with Special Health Care Needs in the COVID-19 Pandemic" https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic/
14. Eighth Broadband Progress Report https://www.fcc.gov/reports-research/reports/broadband-progress-reports/eighth-broadband-progress-report https://docs.fcc.gov/public/attachments/FCC-20-50A1.pdf
15. National Center for Education Statistics https://usafacts.org/articles/internet-access-students-at-home/

16. The National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh. Effects of COVID-19 on Family Caregivers: A Community Survey from the University of Pittsburgh. https://ucsur.pitt.edu/files/center/covid19_cg/COVID 10_Full_Report_Final.pdf
17. Allshouse C, Comeau M, Rodgers R, Wells N. Families of Children with Medical Complexity: A View from the Front Lines. *Pediatrics.* DOI:https://doi.org/10:1542/peds2017-12840
18. More information on Home and Community Based Services:
    -https://www.medicaid.gov/medicaid/home-community-based-services/index.html
    -https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs
    -https://www.kidswaivers.org/
19. Center for Medicare/Medicaid Services: COVID-19 Emergency Blanket Declarations for Health Care Providers.
    https://www.cms.gov/files/document/covid19-emergency-declaration-health-care-providers-fact-sheet.pdf 3.30.20
20. Center for Medicare and Medicaid Services: Physicians and Other Clinicians: CMS Flexibilities to Fight COVID-19. https://www.cms.gov/files/document/covid-19-physicians-and-practitioners.pdf
21. Center for Medicare and Medicaid Services: Home Health Agencies: CMS Flexibilities to fight COVID-19. https://www.cms.gov/files/document/covid-home-health-agencies.pdf
22. U. S. Department of Health and Human Services: Office of Civil Rights in Action
    https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog
23. US Department of Labor. COVID_19 and the Family and Medical Leave Act Questions and Answers https://www.dol.gov/agencies/whd/fmla/pandemic
24. Courtenay K, Perera B. COVID-19 and people with intellectual disability: impacts of a pandemic. *Ir J Psychol Med*. 2020 May 14 : 1–6. doi: 10.1017/ipm.2020.45 Published online 2020 May 14. PMCID: PMC7287305. PMID: 32404232
25. Kainth M, Goenka P, Northwell Health COVID-19 Research Consortium, et al. “Early Experience of COVID-19 in a US Children’s Hospital”. *Pediatrics.* October 2020, 146 (4)e2020003186; DOI: https://doi.org/10.1542/peds.2020-003186
26. Alliance for Health Policy: The Immediate and Lasting Impacts of COVID-19 on Children:https://www.allhealthpolicy.org/the-immediate-and-lasting-impacts-of-covid-19-on-children/#:~:text=Although%20evidence%20indicates%20that%20children,the%20pandemic%20is%20adequately%20controlled
27. Maynard R, Christensen E, Cady R, Jacob A, Ouellette, Y; Podgorski H, Schlitz B, Schwantes S, Wheeler, W. Home Health Care Availability and Discharge Delays in Children with Medical Complexity. *Pediatrics.* 2019, 143 (1) e 20181951; DOI:https://doi.org/10.1542/peds.2018-1951
28. American Academy of Pediatrics’ National Resource Center for the Patient and Family-Centered Medical Home. https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx
29. Academy of Family Practice: The Medical Home.
    https://www.aafp.org/family-physician/practice-and-career/delivery-payment-models/medical-home.html
30. American College of Physicians: What is the Patient-Centered Medical Home?
    https://www.acponline.org/practice-resources/business-resources/payment/delivery-and-payment-models/patient-centered-medical-home/understanding-the-patient-centered-medical-home/what-is-the-patient-centered-medical-home

Complex Care
Journal

PANDEMIC IS DECLARED: Early Experience from Families of Children with Medical Complexity during SARS-COV-2 Lockdown: Information to Drive System Change

HASSINGER A & LAIL J

Complex Care Journal 2021; EDITION 2;