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*Article*

## **EXAMINING THE IMPACT OF THE COVID-19 PANDEMIC ON CAREGIVERS OF CHILDREN WITH COMPLEX AND CHRONIC CONDITIONS**

**Molly Greer**  
**Chelsea Pierce**

University of Central Florida

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**Abstract:** In March of 2020 the president of the United States declared a national emergency as COVID-19 transmitted across the globe. Over 18 months later, the pandemic continues to pose challenges as residents of the world adapt to the ever-changing shuffle of precautions, regulations, and restrictions. During this unprecedented time we have globally learned to expect the unexpected; which has become the norm. Caregivers of Children with Complex and Chronic Conditions wear multiple hats when taking care of their children. They may serve as a nurse, therapist, educational advocate, chauffeur, or personal assistant. Due to the ever-changing routines and mandates as a result of the pandemic, parents have become worn down, leading to mental health concerns and caregiver burnout. During the pandemic caused by COVID-19, caregivers of children with unique needs are faced with a new set of challenges

**Keywords:** *complex needs, pandemic, caregiver, COVID-19*

### Vignette

*Rebecca Jones is a full-time working mother with two children, Braxton and Leila. Braxton is a third-grade student who attends public school in a fully inclusive classroom. He has Cerebral Palsy and Dyslexia, and Leila is a seventh-grader with Sickle Cell anemia. Because both children have Complex and Chronic Conditions (CCCs), Rebecca often has to pick them up from school early or keep them at home if they have medical appointments. Braxton has an Individualized Education Plan (IEP) and receives support facilitation services in language arts & math.*

*Additionally, he attends physical therapy, occupational therapy, and speech/language therapy at school on a weekly basis. When not in school, he enjoys participating in adaptive art classes and boy scouts. Leila has an IEP as well and sometimes receives Hospital-Homebound support, as she misses at least six days of school monthly due to pain and hospitalizations. Rebecca is grateful for the support of Braxton and Leila's teachers, therapists, and community. Mr. Jones is the owner of a technology company and works from home most of the time. Since the pandemic's start, Rebecca's company transitioned her position to a fully-remote role. Because Braxton and Leila are medically fragile, Rebecca enrolled both students in fully virtual classes to limit their possible exposure to COVID-19. Unfortunately, this has limited their access to services received in school. Braxton's school tries its best to do virtual Speech and Language therapy, but occupational and physical therapy hasn't been able to conduct sessions virtually. Braxton often complains of missing his peers and doesn't understand why he needs to stay home. While Rebecca is glad she can work remotely while caring for her family, she is struggling. With two children with complex needs, two adults working from home, and a global pandemic, Rebecca and her husband are burnt out.*

### **The Global Pandemic and the Impact on Families and Caregivers**

“It takes a village to raise a child...” For students with complex needs, this multiple disciplinary village often includes educators, therapists, a medical team, and behavioral/mental health supports, who work alongside parents and other community resources. Pre COVID-19, children went to school, received outside therapies, or attended other public activities. Parents had more opportunities to work and manage other responsibilities. However, once the necessary precautions were put in place during quarantine, families became more isolated. Parents assumed new roles as quarantine became the new norm and the demands on parents increased.

As a direct result of the global pandemic, parents and caregivers have been tasked with new roles and responsibilities. While some parents educated their child/ren in the home for a portion of the pandemic, others facilitated their child's learning while attending virtual school. At the beginning of the pandemic, schools closed, teachers spent endless amounts of time preparing lessons for students to complete virtually, and parents took on the responsibility of their student's learning. Houses gained new purpose, kitchens across the world transformed into learning labs, bedrooms into classrooms, and living rooms served as a space for physical education class. In March of 2020, 42% of workers who were once working in a storefront or office space were now working

from home (Wong, 2020), while nearly 93% of students were transitioning to learning from home (McElrath, 2020).

According to the World Health Organization (WHO), people with disabilities may be at a higher risk for COVID-19 due to comorbid health conditions and challenges accessing healthcare services independently. Other factors such as the feasibility of social distancing and the implementation of hygienic practices must also be considered (WHO, 2020). In addition to changes in the mode of academic instruction, families of children with complex and chronic conditions have experienced fluctuations in the continuity of care for medical appointments, limited interactions with peers due to social distancing, and increased caregiver burnout and depression (Dhiman et al., 2020).

### **Complex and Chronic Conditions**

Complex and Chronic Conditions (CCC) consist of “any medical condition(s) that can be reasonably expected to last at least 12 months... and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center” (Feudtner et al., 2000 & 2014).

Depending on individual strengths and challenges, some children with CCCs attend inclusive schools and classes while others enroll in specialized centers or schools with educators equipped with in-depth training to accommodate students’ needs. Some children with CCC are homeschooled or receive hospital-homebound services.

Parents of children with CCC advocate for their unique needs across a variety of settings, ensuring their children receive access to high-quality healthcare, education, and opportunities to engage with others. Although there are programs designed to meet the individual needs of children with common diagnoses, children with CCC often have comorbid medical conditions, compounding the trajectory of suggested interventions. Common services include speech-language therapy, occupational therapy, physical therapy, specialized medical care, respite care, and social and behavioral supports.

While each familial situation is different, common challenges faced by parents of children with complex medical needs include lack of sleep, challenges maintaining a job due to the amount of time dedicated to caregiving, and advocacy responsibilities, and loss of financial income (Pordes et al., 2018).

### **The Weight of the Pandemic**

The sudden halt in “life as we knew it” and the shift to the “new normal” families experienced challenges unlike any they had ever endured before. According to the CDC (2020) and Hamel and colleagues (2020), families with children under the age of 18 reported three major stressors, 1) digital inequity or access to technology, 2) job stability/security, and 3) food security. Each stressor impacts families and caregivers differently; it is essential to understand the scope and magnitude of the impact.

*Digital Equity:* Digital Equity, also known as digital inclusion, is the ability to access and effectively use technology (Sharp, 2020). Caregivers and parents had the responsibility to not only gain access to the technology needed for their children to learn, and become proficient in the use of their student's digital platform to be considered effective. The Pulse Survey, sent by The United States Census Bureau (2020), uncovered that 66% of families with an income of less than \$50,000 were able to access online educational platforms resulting in 21% of families accessing school through paper-based packets sent to families, and sadly 13% of families not able to access school curriculum at all. The percentage of families able to access online resources increased to 77% for families making up to \$99,000 annually and 86% of families making above \$100,000 annually.

Gaining access to the online educational platforms became a challenge for families, yet those families who had access faced another challenge, the number of screens in the household. Parent's working from home required access to their screen to complete their job and students needed access to screens to complete school work, whether that be synchronous or asynchronous. Families reported not having enough screens/devices for their children to attend class at the appropriate time as well as not having the internet capabilities to withstand the bandwidth of both the working parent/caregiver and the students learning online (Sharp, 2020)

*Job Stability/Security:* Parents with students with complex needs take on average 12 more days off than those without children with disabilities. As the pandemic closed the doors of schools, parents and caregivers faced a new stressor: how to manage their jobs and their child's education. A 2020 Catalyst Survey reported that 71% of women and 65% of men had to modify their work routines at the start of the pandemic. This modification of work routine resulted in 43% of parents sharing that they felt unable to perform to the extent their company required of them (Catalyst, 2020). As the demand for education and job performance, parents and caregivers reported that 33% of those parents/caregivers fear being laid off due to their newly acquired responsibilities (Catalyst, 2020).

The same Catalyst Survey (2020) shares that 41% of mothers and 36% of fathers felt the need to hide their caregiver stress from their employers and co-workers, resulting in adverse psychological effects for caregivers. These psychological effects not only impact the parent/caregiver but also their spouse and child in the household. A recent study found that parents with increased job stress due to the pandemic felt as if they were not able to control their frustration effectively and frequently overreacted to small issues with their families (Morelii, 2020).

*Food Security:* In the year 2020, 50.4 million people faced food insecurity, of which 17 million are school-aged children (Hake et al., 2020). As parents/caregivers increasing concerns with job security rose, the fear of not being able to provide food for their family rose. Though food insecurity rose 4.1% across the nation, there was no substantial increase in families applying for food assistance (Hake et al., 2020). Some states began food stamp programs for families with students in school to ease the burden of food costs on families, but personal reports state that those efforts were not enough to cover the increase in food prices at the beginning of the pandemic.

**Parent and Caregiver Burnout**

With stressors as substantial as those listed above, parents and caregivers were given a burden greater than they should bear alone. Parents and caregivers that experienced an increase in pandemic-related stress found it more difficult to understand their child's needs and hardships, and parents/caregivers struggled to respond to their students in a sensitive manner (Spinelli et al., 2020). As the parents' ability to emotionally regulate their emotions changed, children saw a similar shift in their ability to self-regulate (Morelli et al., 2020). Once a family is in a cycle of poor emotional self-regulation, they are at risk of remaining in this unhealthy mental state. Stress cycles and drains the individual, leading to caregiver burnout.

Caregiver burnout is when a parent or caregiver feels overwhelmed by the responsibilities of taking care of others, and this results in their inability to continue to provide effective care. As a caregiver, burnout is common, with approximately 12.7% more than average caregivers expressing they felt burnout with no support available to them. In 2020, 27% of parents reported worsening mental health and feeling unable to support their children the way they felt they should be (Patrick et al., 2020)

**Three Tips for Families and Caregivers to Navigate the Pandemic**

As the impacts of the pandemic continue to influence the daily lives of families across the globe. Below are three tips to help families and caregivers in ways to support their child and themselves in the midst of challenging times.

***Tip One: Advocate***

Continue to advocate for the specific needs of your child. If your child has an Individualized Education Plan (IEP), they are legally entitled to receive all services listed on the IEP whether there is a pandemic occurring or not. If a school does not provide access to specialized services as detailed on their IEP, your child may be entitled to receive compensatory services (Hurwitz et al., 2021). Determine the best method of communication for you and your child's teacher, and request updates and frequent contact to ensure your child is on track.

Advocating is an overwhelming task at some times, especially during a pandemic. It is during these times that it is important to stay current on local, state, and national legislation in the area of pandemic support. Local school districts should provide service plan updates to parents/caregivers of students with disabilities. If you have yet to receive a plan, contact your school and ask for such a plan, especially if your school remains or transitions to online learning. Also, during this time it is hard to remember that this is all still so new for teachers and school districts. Your child's school or teacher might only be able to give updates that reach only a few weeks into the future, and that will be okay. There is still a multitude of unknowns that schools are trying to navigate.

***Tip Two: Practice***

Keep the germs at bay by explicitly teaching physical distancing and hygiene practices in the home (WHO). Children with complex needs may need additional support applying social distancing practices outside of the home. Play social distancing games within the home to solidify their understanding of distancing regulations. Place a timer next to the sink or water source, and practice frequent hand-washing. If your child is medically cleared to wear a mask, add mask-wearing practice into your daily routine at home. The more opportunities for practice at home, the higher the likelihood of successful implementation in public.

Another important piece to practice is a “typical” routine. It is possible that students could be transitioning from school to learning from home to learn as a variety of variants arise. It is crucial for a child's success to continue to practice the school routines. According to the United States Department of Health and Human Services (2020), routines not only provide a consistent structure in which student learning thrives, but routines also provide a sense of security for children to know what is going to happen next. Security in a time of a plethora of unknowns will not only benefit your child but will also benefit you as a caregiver. Having a plan is a good way to start self-care routines as a caregiver

### ***Tip 3: Support***

You are not alone. It is crucial to talk to other parents about the challenges they've faced during the pandemic. Social support helps reduce parental anxiety and stress (Ren et al., 2002). Support groups provide a place to collaboratively brainstorm strategies to simplify complex tasks and routines, create a variety of resources to share among other caregivers, and a place to share your concerns and struggles safely. You may choose to chat with a friend through social media, join a virtual parent support group, or meet up with others in public. Support looks different for every person. Determine what kind of support you need, and reach out.

Caregiver burnout typically isn't felt gradually; instead, it impacts the caregiver in an instant. For most, it feels like you have been hit by a train emotionally, spiritually, and physically. Burnout is among one of the hardest barriers to overcome due to the impact on the whole being of the caregiver. Simple steps of self-care, reaching out for support, and building in accountability systems prevent the suddenness that caregiver burnout can have. Support from others is vital to the well-being of a caregiver. What is most frequently overlooked is the support of one's self. As humans, we are generally our own worst critics. Life happens, your child will have a bad day, you will burn dinner, knock your favorite coffee cup on the floor, or life will seem like it is falling apart at the seams. You are not defined by any of those things. Supporting one's self is the most challenging thing we as humans take on. It is important to remember to give yourself grace in the midst of this chaos. There are still aspects of life that many are unsure of when it comes to the pandemic, and it's okay that caregivers don't know it all or how to do it all. Take time to slow down and reflect on all the good things you are doing. Did you feed your child this morning? Perfect! What a rockstar! Did you get out of bed? Of course! Celebrate that! Celebrate the small things. That is where self-care begins.

### **Conclusion**

For families like the Jones family, the global pandemic will continue to reveal new challenges. Advocating for your support needs as well as your children's specialized support is crucial to thriving during such unprecedented times. The global pandemic has shaken humanity to its core, and we are all trying to navigate through the ever-changing day-to-day routines. Our goal is that caregivers be aware of the stress they are in, the impacts of the pandemic, and ways that they can manage caregiver burnout.

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