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Parenting a child with a chronic illness during a pandemic

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ABSTRACT

Background: Nearly 20% of children in the United States experience one or more chronic health conditions. Parents of a child with a special healthcare need (CSHCN) experience increased stress caring for a child with chronic illness.

Purpose: The purpose of this descriptive study is to describe stress in parents of a child with chronic illness during the COVID-19 pandemic.

Methods: Parents of CSHCN ($n = 34$) were asked to fill out the Pediatric Inventory for Parents (PIP) and answer two questions related to caring for their child during the COVID-19 pandemic.

Conclusions: The means of the PIP-F ($M = 146.6$, $SD = 20.5$) and PIP-D ($M = 141.9$, $SD = 23.9$) were significantly higher than in previous studies. There is statistically significant positive correlation between parent stress and variables of age of the child and the length of time since diagnosis. In response to the questions about the impact of COVID, nearly all parents reported COVID increased their stress and reported their stress was related to isolation, lack of resources, and concern for the mental health of other children in the household.

Practice implications: COVID-19 likely exacerbated feelings of stress for parents of children with chronic health conditions. Although unprecedented, COVID-19 shed light on the existing fragility and high stress of parents of CSHCN. Pediatric nurses not only care for children, but must be advocates for the mental health of their patient's parents.

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Introduction

Advances in neonatal and pediatric medicine have significantly improved survival rates for children with special healthcare needs (CSHCN) over the past two decades. In fact, 90% of children with conditions thought to be fatal in childhood now reach adulthood (Cohen et al., 2011). Such conditions, including congenital heart defects, cancer, and cystic fibrosis, are now managed with long-term treatment (Compas et al., 2012). Management often includes caring for chronic physical, developmental, behavioral, or emotional conditions. These conditions may be mild or severe. Care is often provided or managed by parents rather than healthcare professionals. There are 14.6 million CSHCN in the United States (US), representing 19.8% of American children (US Department of Health and Human Services, 2013).

Parents of CSHCN experience challenges that parents of healthy children do not. For example, a healthy child may be able to tie their shoes,

leave the house, get into a car, and buckle their own seat belt without assistance. In contrast, a CSHCN may require a dedicated caregiver, specialized equipment, and medical considerations to accomplish the same tasks. In addition to typical caregiver tasks, parents of a CSHCN may experience added stress related to illness management, uncertainty of the child's condition, financial resources, time conflicts, and guilt (Golfenshtein et al., 2016).

It is not surprising that parents of CSHCN are more likely to experience stress, anxiety, depression, and post-traumatic stress disorder than parents of healthy children (Casaña-Granell et al., 2018; Gannoni & Shute, 2010; Pinquart, 2018). In addition, in a meta-analysis, Pinquart (2018) found higher health-related parent stress was associated with higher severity and longer duration of the child's condition, while parents of older children reported lower health-related parenting stress.

Over 50% of parents of CSHCN reported depressive symptoms (Churchill et al., 2010) and only half of those reporting depressive symptoms felt they were able to cope effectively (Child and Adolescent Health Measurement Initiative, 2012). There is some evidence that demographic characteristics such as child's illness severity and duration, child age, parental gender, marital status, marital

Abbreviations: CMC, children with medical complexity; CSHCN, children with special healthcare needs.

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quality, and levels of perceived support affect stress levels. For example, mothers report higher levels of parenting-related stress than fathers across the board; however, both genders report higher levels of stress when they have a CSHCN in the home (Golfenshtein et al., 2016).

Psychological stress in parents is concerning because it negatively impacts family function as a whole and may also negatively influence their child's level of adjustment to the illness (Casaña-Granell et al., 2018). Although not specifically researched in parents of CSHCN, the health risks of stress have been documented and a recent systematic review found that the effects included poor general physical health, increased pain and disability, lower quality of life, and higher risk of all-cause mortality (Garfin, Thompson, & Holman, 2018). Recently, a systematic review by Hartley et al. (2021) found that in 84% of the studies, caregiver health was negatively impacted, with pain and sleep problems leading the list.

The COVID-19 pandemic began in the US in early 2020. Most communities faced lockdowns by March 2020, where non-essential travel was discouraged, schools were closed, masks were encouraged, and supply and workforce shortages were common (AJMC Staff, 2021). These restrictions were gradually relaxed during the remainder of 2020, and COVID-19 vaccinations began to become available in early 2021 for adults and adolescents, and later for school-age children. However, vaccines have yet to be available for children less than 5 years of age. Rates of infection have continued to rise and fall with the presence of variants of the virus and regional variation in the uptake of the COVID-19 vaccine.

Little is known about the stress levels and experiences of parents as caregivers during the pandemic. During the pandemic parents were more likely to spend more time caring for their children within the home with minimal outside contact than before. This allowed researchers the opportunity to study parent perceptions of stress related to caring for a CSHCN during this challenging time; this is important because parent caregivers of CSHCN are at higher risk for isolating events that may increase stress such as lack of caregivers, illness, or natural disasters (CDC, 2021). During the pandemic many families struggled to find qualified home health nursing care for their children. A better understanding of caregiver stress during the pandemic may help healthcare providers better understand caregiver stress and improve options for support and management. Therefore, the purpose of this study is to explore parental stress in parents of children with a chronic illness during a pandemic. The specific aims for this study are: (1) describe stressors associated with caring for a child with chronic illness; (2) describe whether demographic variables affect stress levels; and (3) describe how the pandemic has impacted their ability to care for their child.

Methods

Design

We used an exploratory, descriptive correlational study design to describe the variables and examine the differences based on certain demographic characteristics (Gray & Grove, 2021).

Procedures

Following approval by the institution's Institutional Review Board (IRB), we invited parents to participate in our study. We recruited participants through social media sites (Facebook, Nextdoor) and a local non-profit organization with a mission aimed at providing support to families of rare diseases in the Northwest. We provided information about the study and, if they agreed to participate, parents filled out the study questionnaire through an email link.

Setting and sample

We aimed to recruit from the community and a local non-profit organization. Recruitment started with the social media sites, however after three weeks of recruitment, no participants had expressed interest. The recruitment started through the non-profit organization, and we ended up recruiting a convenience sample of 34 mothers from a local non-profit organization. The non-profit organization provides services for families within a 30 mile radius of the urban setting. Currently, they provide support, ranging from meal services, snow removal, housekeeping, and support groups to 115 families. The target population was not limited to parents with a child who had a specific condition or diagnosis.

Measures

Demographic questionnaire

Parents completed a demographic questionnaire assessing demographic characteristics such as family income, caregiver age, marital status, education, time since child's diagnosis, number of providers, and number of family members in the home.

The Pediatric Inventory for Parents (PIP) (Streisand et al., 2001) is a 42-item self-report tool that was developed to measure parenting stress related to caring for a child with an illness. For each item, parents rate the frequency of an event as well as how difficult/stressful the event is on a 5-point Likert scale. Frequency and difficulty scores are individually summed to yield PIP Frequency (PIP-F) and PIP Difficulty (PIP-D) scores (range 42–210) with higher scores indicating greater parenting stress. Scoring consists of an overall score and 4 subscores (communication, medical care, role function, and emotional function). Cronbach's coefficients for the total scale are strong (PIP-F = 0.95, PIP-D = 0.96) and range from 0.80 to 0.96 for the subscales (Streisand et al., 2001).

Pandemic-related questions

We asked parents to describe whether the pandemic had increased, decreased, or not changed their stress. We also asked one open-ended question: "Please describe how the COVID-19 pandemic has affected your ability to care for your child."

Data analysis

We analyzed quantitative data using Statistical Package for Social Sciences (SPSS, IBM, v. 27). We used descriptive statistics to describe the demographic variables as well as the PIP subscales and total score. We used inferential statistics (student's *t*-test, ANOVA) to determine whether stress differed based on demographic variables. We analyzed qualitative data using thematic analysis (Morse & Field, 1995). Survey comments were downloaded and the text was read repeatedly to achieve comprehension of the data. Comments were synthesized and sorted and "fit" into tentative themes. Each researcher initially completed this process independently, and then the team came together to compare and identify consistent themes. Final themes explaining the data were agreed upon by the entire research team.

Results

Our participants consisted of 34 mothers who ranged in age from 21 to 60 years of age ($M = 38.7$; $SD = 8.3$). Most parents were either married or living with a partner ($n = 27$), white, non-Hispanic ($n = 32$; 96.9%), and had attended some college ($n = 31$, 93.9%) (Table 1). Of the 34 children involved, the majority were female ($n = 18$) and the ages of children in the study ranged from seven months to 19 years. Children had an average of four chronic conditions as reported by their parents. The most common diagnosis was neurodegenerative disease, followed by gastrointestinal and hematological conditions.

Table 1
Demographics of participants.

Parent Demographics	
Age (Mean; SD)	38.7 (8.3)
Gender (n, %)	
Female	34 (100)
Male	
Race/Ethnicity (n, %)	
White/Non Hispanic	32 (94.1)
Native Hawaiian or other Pacific Islander	1 (2.9)
Hispanic, Latino, or other Spanish	1 (2.9)
Education (n, %)	
High school or less	3 (8.8)
Some College	9 (26.5)
College	9 (26.5)
Some graduate school	6 (17.6)
Graduate School	7 (20.6)
Income (n, %)	
<\$25,000	4 (11.8)
\$25,000–\$49,999	5 (14.7)
\$50,000–\$74,999	6 (17.6)
\$75,000–\$99,999	6 (17.6)
\$100,000–\$148,999	6 (17.6)
>\$150,000	1 (2.9)
Marital Status (n, %)	
Single	2 (5.9)
Married	28 (82.4)
Divorced	4 (11.8)
Family Size (n, %)	
2	1 (2.9)
3–4	18 (52.9)
5–6	10 (29.4)
7–8	5 (14.7)
Child Demographics	
Gender (n, %)	
Male	16 (47.1)
Female	18 (52.9)
Age (Mean, SD)	8.8 (5.5)
# of Providers Child Sees (n, %)	
3–5	6 (17.6)
6–9	18 (52.9)
10+	10 (29.4)
# of Provider Visits in Past 6 Mos (n, %)	
≤2	1 (2.9)
3–5	4 (11.8)
6–10	11 (32.4)
11–15	9 (26.5)
>15	9 (26.5)
Time since Diagnosis (n, %)	
<1 year	3 (8.8)
1–2 years	3 (8.8%)
3–5 years	9 (26.5%)
6–9 years	7 (20.6%)
10+ years	12 (35.3%)
Type of School/Class (n, %)	
Regular class	1 (2.9%)
Full time personal assistant	1 (2.9%)
Special education	18 (52.9%)
Homeschool	4 (11.8%)
Not in school	10 (29.4%)

Research Aim 1: Describe parenting stress

Descriptive statistics for the parenting stress subscale and total scores are presented in Table 2. The total score for PIP-F was 146.6 (20.5) and PIP-D was 141.9 (23.9). Overall, the subscale with the highest score was Emotional Distress, whereas the lowest score was Communication.

Research Aim 2. Describe the effect of demographic variables on stress

Parenting stress frequency and difficulty scores did not significantly vary by parental demographic variables (i.e. marital status, education,

income), but did vary by child variables (i.e age, time since diagnosis). Child's age was weak to moderately correlated with the PIP-D, $r(32) = 0.483, p = .004$ and PIP-F, $r(32) = 0.440, p = .009$. The subscales that were also correlated included: Communication-D ($r = 0.450, p = .008$), Emotion-F ($r = 0.359, p = .037$), Emotion-D ($r = 0.385, p = .025$), Role function-F ($r = 0.377, p = .028$), and Role function-D ($r = 0.483, p = .004$). There was a significant effect of time since diagnosis on PIP-F [$F(2,31) = 4.02, p = .028$] and PIP-D [$F(2,31) = 4.22, p = .024$]. Post hoc analyses using the Bonferroni post hoc criterion for significance indicated that the PIP-D and PIP-F scores were significantly higher in parents whose children had been diagnosed more than 10 years ago compared to parents whose child was diagnosed less than 2 years ago (see Fig. 1).

Research Aim 3. Describe how COVID-19 affected a parent's stress level and ability to care for their child

Parents were asked two questions related to caring for their child during the pandemic. The first question asked them to rate how the pandemic had affected their stress and the second question asked them to respond to the question, "Please describe how the COVID-19 pandemic has affected your ability to care for your child". Of the 30 parents (88%) that answered the first question, 27 parents (90%) indicated that the pandemic increased their stress, 1 parent (3%) indicated that it lowered her stress, and 2 parents (7%) indicated that it didn't impact their stress. 30 participants (88%) answered the second question (see Table 3). The majority of parents mentioned the isolation they experienced and expressed concerns over lack of support. Parents also discussed the effect the isolation had on their mental health as well as that of other children in the home. Access to telehealth was viewed both positively and negatively. Two parents mentioned that when telehealth appointments became available, it was easier and less stressful to receive care. However, one parent mentioned that it was difficult to communicate effectively using telehealth.

Discussion

The convenience sample for this study ended up consisting of children with more than one chronic illness and their acuity level was more consistent with the definition of children with medical complexity. Although no standard definition of medical complexity exists, four domains characterize CMC: 1) chronic, severe health conditions; 2) substantial health service needs; 3) major functional limitations; and 4) high health resource utilization (Cohen et al., 2011). It is estimated that CMC makes up approximately 3.2% of CSHCN or 0.4% of all children in the US, which is approximately 3.6 million children (Gallo et al., 2021). However, this subgroup is increasing at a rate of approximately 5% per year, exceeding the growth rate of the children as a whole (Gallo et al., 2021).

The results of the quantitative study demonstrate the high stress that these parents are experiencing and the quantitative results provide a glimpse into the experiences of parents during the pandemic. Parents in this sample reported significantly higher levels of stress, both frequency and difficulty, in all areas compared to other studies (see Table 3). It is difficult to determine if this is related to the pandemic or child's medical complexity in this sample. However, researchers found that parents of CMC, compared with parents of CSHCN and non-CSHCN, were at a much higher risk for developing mental health issues (Bayer et al., 2021; Hartley et al., 2021). The qualitative responses by parents in this study suggest that the pandemic has had a negative impact on their mental health and wellbeing. Numerous studies have shown that both mothers' and fathers' internal characteristics, such as their mental health (Vallotton et al., 2016), parenting stress (Lee & Noh, 2017; Stone et al., 2016), and depression (Cummings et al., 2005; Goodman et al., 2011), are closely related to social, emotional and behavioral problems in their children.

Table 2
Pediatric Inventory for Parent (PIP) scores: Current sample and previous studies.

PIP	Current sample	IBD (n = 62)	Cancer (n = 126)	Heart Transplant (n = 52)	Diabetes (n = 134)	SCD (n = 70)
Total						
Frequency	146.6 (20.5)	84.4 (27.9)	94.0 (33.3)	112.4 (24.6)	89.3 (26.0)	105.4 (27.3)
Difficulty	141.9 (23.9)	78.2 (25.2)	112.4 (35.1)	102.3 (26.2)	78.1 (26.1)	91.1 (33.0)
Communication						
Frequency	27.8 (4.5)	17.8 (5.5)	18.0 (6.7)	22.7 (5.4)		
Difficulty	25.7 (6.4)	14.3 (4.7)	19.8 (7.4)	18.3 (5.3)		
Medical Care						
Frequency	30.8 (5.3)	15.9 (6.6)	16.1 (7.1)	22.9 (6.6)		
Difficulty	27.0 (4.7)	12.4 (4.6)	19.3 (7.4)	16.8 (5.2)		
Role Function						
Frequency	32.7 (6.1)	18.2 (6.9)	20.6 (8.1)	24.3 (6.9)		
Difficulty	33.7 (7.1)	17.3 (6.0)	29.9 (9.3)	23.4 (7.3)		
Emotional Distress						
Frequency	55.3 (8.2)	33.0 (11.6)	39.2 (14.6)	42.6 (10.4)		
Difficulty	55.5 (9.5)	34.8 (13.1)	48.4 (14.5)	43.8 (13.4)		

IBD, inflammatory bowel disease (Guilfoyle et al., 2014); Cancer (Streisand et al., 2001); Diabetes (Streisand et al., 2005); SCD, sickle cell disease (Logan et al., 2002); Heart transplant (Farley et al., 2007); PIP subscales scores were not available for all samples.

In this study, parents whose children were diagnosed more than 10 years ago had significantly higher PIP-F and PIP-D scores than parents whose children had been diagnosed less than two years ago. While anxiety is only one part of overall parenting stress, a study by Toledano-Toledano and Moral de la Rubia (2018) did not find a statistically significant difference in anxiety based on time since diagnosis, which was counter to the results of this study. This finding may reflect the increased caregiving needs and more complex care coordination that older children may require.

Parents described how the pandemic both increased their stress levels and affected their ability to care for their child and family as a whole. For example, parents in this study expressed concern about how the pandemic and isolation at home affected siblings' mental health, specifically depression. During the pandemic, healthy children were also isolated due to school and extracurricular closings and the worry and fear of bringing COVID into the home may have contributed to the mental health burden of the entire family.

The impact of a child's chronic illness on siblings has been well documented. For example, a metasynthesis of 12 qualitative studies about siblings' experiences living with a CSHCN revealed that many siblings experience difficulty communicating with their parents and an overall negative sense of self (Deavin et al., 2018). Many siblings reported worrying about their ill sibling's health and well-being, to the point of interfering with school, causing general anxiety, and feelings of loneliness and isolation. Sadly, some siblings even call themselves "the most unhappy member of the family" (Deavin et al., p.6). It is clear from this synthesis and from our study that parents have challenges caring for not only their CSHCN, but with siblings as well.

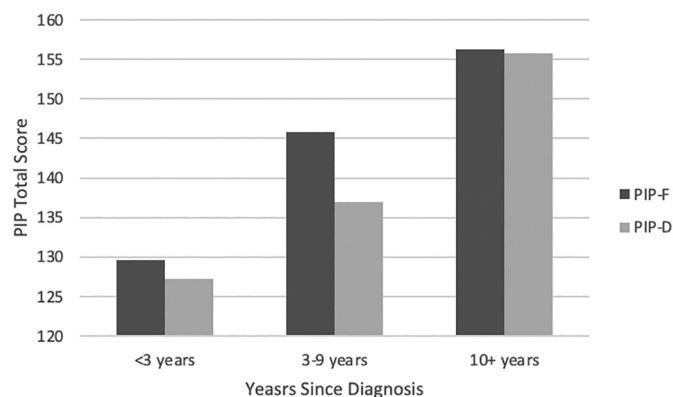


Fig. 1. Effect of Years Since Diagnosis on PIP Total Score. PIP-D, $p = .024$; PIP-F, $p = .028$.

Telehealth was viewed both negatively and positively. Done properly, telehealth may be a positive outcome of the pandemic. Parents of a CSHCN likely have several visits with various healthcare providers. It can be costly and challenging for parents to physically get to these appointments due to their child's needs, transportation requirements, getting time off of work, and other family responsibilities. This finding is consistent with a prior study where parents of children with complex conditions described caregiver strain due to difficulties with missing work, delaying schooling, and passing on job offers and promotions (Koch et al., 2021). Telehealth offers benefits such as minimizing lost work time, minimizing missed schooling for the child, reducing the stress of transportation and managing a CSHCN out of the home, and allows the provider to see the patient and family in their home environment. However, one parent in this study felt communication was challenging via telehealth. These findings are consistent with other findings about using telehealth during the pandemic, as the most commonly cited benefits of telehealth included access to care and the ability to isolate during the pandemic, while the barriers included difficulties with technology and communication (Monaghesh & Hajizadeh, 2020). Healthcare workers should be mindful of these concerns and ask parents their preference for appointments and take steps to minimize difficulties with communication on the telehealth platform.

Although the purpose of the study was aimed at parenting stress, many of the participants reported worsening mental health for themselves and their family. These findings are validated by data from the United Kingdom collected during the pandemic that showed increases in worry, loss, and depression among families of children with special health care needs (Asbury et al., 2021). It is well known that, in general, parents of chronically ill children have increased rates of anxiety and depression than parents of healthy children (Cohn et al., 2020).

Limitations

Several limitations affect the generalizability of our study. First, the small sample size ($n = 34$) and timing of the study (during a pandemic) limit the generalizability of our study. In addition, the sample was primarily female, educated, and White/Caucasian. This may be related to the fact that this sample was recruited from a non-profit organization. There is some evidence to suggest that education and income can increase social capital, resulting in greater access to resources (Pampel et al., 2010). In addition, because parents were recruited through a non-profit organization aimed at providing support for families of children with rare diseases, the parents represented might have children with a higher acuity of chronic illness, thus limiting the generalizability of the findings.

Table 3
Responses to open ended question (n = 30).

Topic	Number of Participants	Quotes
Isolation	N = 17 (57%)	<p>"Caring for a medically fragile child is isolating in the best of times, now it's excruciatingly so. I'm on the verge of panic attacks over small things, and feel like what little support we ever had is gone, and may never come back, due to Covid denial."</p> <p>"We do not go anywhere except dr appointments. We have been stuck inside the house for months and it is mentally hard and exhausting."</p> <p>"We've both been in lock down, keeping siblings out of public spaces and worrying about people in our circle that do not wear masks or believe in the pandemic! Not being able to work, or have interactions has caused depression for my teens and I'd say slightly for me. Worrying about seeing my son on a respirator again because of this and some people seeming not to care or believe it, breaks my heart!"</p>
Lack of Support and socialization (school, therapy, caregivers, sitters)	N = 14 (47%)	<p>"I've had to be home with her 100% because school isn't safe. She gets fewer therapies because the clinics aren't all safe. I worry about her getting sick and hospitalized and the hospital be stressed for the resources she needs to save her life."</p> <p>"My son no longer attends school regularly. This is where he is able to be social with teachers and peers that are not afraid to interact with him. HE LOVES SCHOOL."</p> <p>"His services have drastically changed at school and slightly with his medical team. It is hard to help him continue to keep moving forward when he is isolated and not getting experience being with others in social situations. He's growing increasingly irritable at noises and other stimuli and becoming intolerant of being around others as a result of so many months of isolation."</p>
Effect on siblings	N = 5 (17%)	<p>"Covid has taken all normalcy from our life. My daughter is high risk and therefore she is not able to attend school. Because of her status her sister is unable to attend in person school either. We have been isolated. It has been depressing and stressful during this time not only for me but for both of my children as well."</p> <p>"We've both been in lock down, keeping siblings out of public spaces and worrying about people in our circle that do not wear masks or believe in the pandemic! Not being able to work, or have interactions has caused depression for my teens and I'd say slightly for me. Worrying about seeing my son on a respirator again because of this and some people seeming not to care or believe it, breaks my heart!"</p>
Keeping them safe	N = 5 (17%)	<p>"We can't send her to school. She has to be protected so I am very vigilant regarding masks and the CDC guidelines. My anxiety over keeping her safe from the virus has made working more difficult, and I get angry when people are selfishly not wearing masks or wearing them incorrectly."</p>
Access to telehealth	N = 3 (10%)	<p>"Virtual appts can be positive in a way that we don't have to travel to the doctor's office as often but it also set her back in progress a ton. And she hasn't been able to go to school with is sad for her."</p> <p>"She did not have in person therapy for a long time. Doctor visits were over the phone so it was difficult to discuss what was wrong with my child without being able to show them."</p>

Conclusion

Parenting a child with a chronic illness during a pandemic is isolating, challenging, and extremely stressful for parents. It is well known that parents of a CSHCN may experience high levels of stress, anxiety, and depression and the pandemic added to the stress and negatively impacted the emotional and mental health of families. This study is one of the first studies to provide a picture of caring for CMC during the pandemic. Nurses have the unique opportunity to develop meaningful relationships with families. As a pediatric nurse, it is important to assess the parent for feelings of isolation, stress, anxiety, and depression and recommend mental health resources if needed. Asking parents about their feelings and experiences may help them feel they are being heard by their children's healthcare providers. Ensuring the parents are caring for their own needs is essential for the well-being of the family unit, including CSHCN and the siblings. Future research opportunities include interventions to support families and educational initiatives to encourage nurses to screen parents for mental health wellbeing.

Declarations of interest

None.

Credit authorship contribution statement

Cara Gallegos: Conceptualization, Methodology. **Michael D. Aldridge:** Methodology. **Lauren Zuba:** Writing – review & editing.

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