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# Persistent Symptoms and Conditions Among Children and Adolescents Hospitalized with COVID-19 Illness: A Qualitative Study

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<th>Journal:</th>
<th><em>BMJ Open</em></th>
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<td>Manuscript ID</td>
<td>bmjopen-2022-069073</td>
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<tr>
<td>Article Type:</td>
<td>Original research</td>
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<tr>
<td>Date Submitted by the Author:</td>
<td>10-Oct-2022</td>
</tr>
<tr>
<td>Complete List of Authors:</td>
<td>Messiah, Sarah; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences; University of Texas Health Science Center, School of Public Health Francis, Jackson; The University of Texas Health Science Center at Houston Weerakoon, Sitara; The University of Texas Health Science Center at Houston, Mathew, M.; The University of Texas Health Science Center at Houston Shaikh, Sumbul; Children’s Health System of Texas Veeraswamy, Apurva; Southern Methodist University Lozano, Alejandra; Children’s Health System of Texas He, Weihen; Texas Tech University Health Sciences Center El Paso Xie, Luyu; The University of Texas Health Science Center at Houston, Center for Pediatric Population Health Polavarapu, Dhatri; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences Ahmed, Nabila; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences Kahn, Jeffrey; The University of Texas Southwestern Medical Center</td>
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<td>Keywords:</td>
<td>Paediatric infectious disease &amp; immunisation</td>
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Persistent Symptoms and Conditions Among Children and Adolescents Hospitalized with COVID-19 Illness: A Qualitative Study

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Running Title: Persistent COVID in Children

Word Count: 3449

Number of Tables: 2
Number of Figures: 0

Conflicts of Interest: The authors declare no conflicts of interest

Financial Support: None

Ethical Approval: The Institutional Review Board at the University of Texas Health Science Center ruled this study to be exempt from review and informed consent because of the use of publicly available, de-identified data for analysis.

Data sharing statement: The data and codes generated during and/or analyzed during the current study are available from the first author(s) upon reasonable request.

Author Contributions: SM and JF conceptualized and designed the study, drafted the initial manuscript, and carried out the initial analyses. JK and LX provided clinical guidance, critically reviewed the manuscript for important intellectual content, and revised the manuscript. SM and MM coordinated and supervised data acquisition, reviewed and revised the manuscript. JF, SW, SS, AB, AL, DP, and NA conducted all qualitative interviews. SM supervised data analyses, interpretation of results, reviewed and revised the manuscript. All authors read and approved the final version.
Abstract

Objectives: There is limited in-depth research exploring persistent symptoms and conditions among children and adolescents who contracted COVID-19 illness that required hospitalization. The main objective of this study was to conduct qualitative interviews among families who had a child hospitalized with COVID-19 illness to elucidate their child’s physical, mental, and social health outcomes months after initial acute infection.

Design, Setting and Participants: A qualitative study that comprised of in-depth interviews among families with a child hospitalized with COVID-19 illness in one large urban US pediatric healthcare system. Parents (N=25) were recruited from an ongoing quantitative study to estimate the prevalence of long COVID in children hospitalized with COVID-19 illness. During in-depth interviews, parents were invited to describe their child’s post-COVID symptoms and experiences. Interviews were audiotaped, transcribed, and coded in NVivo.

Results: Seven themes were identified concerning the child’s prolonged COVID-19 experiences; (1) post-traumatic stress disorder, (2) social anxiety, (3) severe symptoms upon re-infection, (4) worsened pre-existing conditions, (5) lack of insurance coverage for costly treatments, (6) access and utilization of support systems, and (7) overall resilience and recovery. Four parent-specific themes were identified; (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) schools being both a support system and a hindrance, and (4) desire for, and access to support systems.

Conclusions: A subset of children who were hospitalized with COVID-19 illness are experiencing a range of serious mental health impacts related to persistent COVID symptoms.
Clinical and public health support strategies should be developed to support these children and their families as they re-integrate in school, social and community activities.

**Key Words:** children, long COVID, persistent COVID, adolescents, illness

**Strengths and limitations:**

- Qualitative, in-depth interviews captured the unique experiences of long COVID among a sample of children who were hospitalized with COVID-19 illness.

- Experiences of long-COVID were captured among a vulnerable pediatric sample.

- Because of the limited sample size, generalizability to larger populations, and other demographics may not be possible.

- Causal inferences cannot be made between patient-reported long COVID-related symptoms and the COVID infection itself.
Introduction

As of September 15, 2022, there have been almost 14.7 million documented COVID-19 cases in the United States pediatric population. Data shows that the majority of COVID-19 cases in children and adolescents are asymptomatic and do not typically require hospitalization. However, the Centers for Disease Control and Prevention (CDC) reports that over 1,200 children and adolescents through age 18 years have died from COVID-19 illness. A small proportion of children with COVID-19 illness are at risk for developing a novel Kawasaki-like disease called multisystem inflammatory syndrome in children (MIS-C). As of September 25, 2022, there have been 8,862 MIS-C cases reported in children, most with a positive SARS-CoV-2 test result.

Irrespective of hospitalization status, some children infected with SARS-CoV-2 can develop symptoms or complications that last for several months, but are typically less severe than those in adults. Symptoms that persist after acute COVID-19 illness are called various names; long COVID, post-acute sequelae of SARS-CoV-2 [PASC], post-COVID-19 syndrome, long-haul COVID, and chronic COVID syndrome. To date, long COVID has been shown to consist of over 200 symptoms, including fatigue, sleep disturbance, concentration difficulties, loss of appetite, muscle or joint pain, pulmonary fibrosis, myocardial dysfunction, and mental health conditions.

At this time, there is no standardized definition of long COVID-19 in adults, and the quality of evidence is still developing. In children, there is a general lack of data regarding long COVID, especially among those diagnosed with MIS-C versus those not diagnosed with MIS-C, and in children less than 11 years old. It is important to assess the incidence and prevalence of long COVID in children as it may impact their social, emotional, mental, and physical health, as well as academic performance, all of which have the potential to impact a child’s quality of life.
even beyond the pediatric years.\textsuperscript{11} Yet, there are very few studies that have qualitatively, or assessed in-depth the social and mental impacts of COVID-19 illness in children. This is especially true for those children most severely impacted by COVID-19 illness coming from diverse backgrounds. Therefore, the aim of this study was to conduct qualitative interviews among families who had a child who was hospitalized with COVID-19 illness among a sample of ethnically and socioeconomically diverse children. It was hypothesized that parents would identify new symptoms and experiences from the standard CDC list currently available.

Methods

We report here results from an exploratory qualitative study using semi-structured in-depth interviews. The study is reported following the Standards for Reporting Qualitative Research framework (SRQR).\textsuperscript{12}

Participants

Using convenience and volunteer sampling, a total of 25 parents were recruited between March 2021 and April 2022. Participants were eligible if they had previously reported in an ongoing quantitative study conducted during the same time period that their child was experiencing long-COVID or post-COVID conditions and had consented to participate in an in-depth interview at a later date. The UTHealth Committee for the Protection of Human Subjects approved all aspects of the current study (study number HSC-SPH-20-1133).

Study Recruitment
As part of a larger quantitative study among a large sample of children hospitalized for COVID-19 illness, parents were asked if they would be interested in also participating in an in-depth interview at a later time. Among those parents who expressed interest in participation, research team members called a maximum of three times to schedule an interview. Participants provided informed and written consent prior to taking part in the interview. All qualitative interviews that are reported here took place between January and April, 2022.

Data Collection

Interviews were conducted by five graduate-level qualitative research-trained team members [SS, JF, WH, AL, AV], with AL conducting all Spanish interviews. A semi-structured interview guide was developed, informed by our quantitative study findings, the literature, study aims, and the research team’s expertise (See Table 1). The guide was iteratively reviewed throughout the study. Interviews were conducted on the telephone, audio recorded, and later transcribed by an external provider. Interviews lasted between 10 and 32 min (mean average = 21 min). Data collection was terminated once no further categories were identified. All participants received a $25 gift card as compensation for their time and participation.

Data Analysis

Data were analyzed using an inductive coding approach. Initially, the first authors [JF, SEM] read and re-read all transcripts while taking reflective notes. Line-by-line coding of the first five transcripts was conducted to create an initial list of codes, which were reviewed and refined with the research team through critical dialogue. All transcripts were imported to NVivo Pro v12 and codes were created to systematically capture interesting aspects of the data across the entire dataset. The initial list of codes was further extended and refined throughout the entire
coding process. To promote study rigor and maintain a connection to the project, 25 transcripts were second coded by the 5 co-authors [JF, SW, DP, NA, AL]. Themes were identified based on the existing coding and organized into themes. The final set of themes was refined through discussions with the research team.

Results

After conducting our interviews and performing the subsequent analysis, we derived the results shown below in Tables 1 and 2. The themes identified fall into two broad categories; themes that relate to the pediatric patient who experienced the COVID-19 illness (Table 1), and themes that relate to the parents of patients, and their experiences caring for a child with long-COVID (Table 2).

<table>
<thead>
<tr>
<th>Theme Name</th>
<th>Theme Description</th>
<th>Supporting Quote(s)</th>
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</table>
| Social anxiety and depression | Mental health issues among children during COVID infection involve anxiety, depression, irritation, and hallucinations. Some children did not experience any mental health issues. Most children recovered from these symptoms, but a few still have persistent symptoms. A couple of children experienced difficulty in speech. | "In school, if someone is talking loudly or making more noise, she gets anxiety."  
"She is afraid of separation from me [the mother]."  
"Doesn’t want to go out, cries and says just get something for me. I don’t want to go out." |
during the infection, but the parents are not sure if it is related to COVID infection or not.

<table>
<thead>
<tr>
<th>PTSD-like symptoms</th>
<th>All patients reported fully recovering from any behavioral changes; changes included tiring easily, hearing and seeing things that weren't there, loss of appetite, speech delay, some children still fear going out in public.</th>
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<tbody>
<tr>
<td>&quot;Mom! Why are you crying?&quot; Probably like 20 times a day she would say that. And I was like 'I'm not crying'. That night she came up and she was hysterical and she was brushing stuff off of her and I was like 'what are you doing?' She's like 'there's ants or spiders crawling all over me'. The next day she was still hearing crying and I was like 'there's something going on'. We all went to bed and she wasn't asleep yet, she kept hearing a noise and she said she saw a monster and was so terrified. I've never seen her so horrified and just hearing and seeing things. She drew in her journal, the monsters. She was like 'I was frozen I couldn't move because there was a monster.' and so she drew the monster...so I called the pediatrician and she said maybe bring her to the ER. You know she never had a fever. I, myself, had one hallucination and it was very, very brief. I did not have a high fever. I saw some monkeys- it sounds totally crazy. I was totally awake; it was in the middle of the day and I saw it and I was like 'that is not supposed to be here' and then it, like, went away. And I wasn't freaked out because I read that it could be a symptom so I didn't freak out...I knew that she was probably having hallucinations. I mean, I don't know if it could have all been anxiety but hearing her tell the story and seeing her...I've never seen her like that before and it was terrifying.&quot; Mother said she didn't have any other major symptoms, she never had a bad fever or headaches, etc.&quot;</td>
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"it's kind of difficult because at the beginning he didn't want to go outside because he heard the news and everybody's saying if you contact people and they have the covid, they will get it again, so it was kind of difficult for him. I mean, for everybody."
"She's more afraid to go out in public. She doesn't really want to go out anymore because of [having COVID], since she had COVID two years ago."

"She didn't fully get back to herself probably until like maybe that last week of December. You know it was to the point where I wasn't having to force her to eat, she would come to me and let me know that she was hungry so I knew it was different. Because you know at first I would have to wake her up to eat but once she started staying up, and she was more alert, and then she would come to me to let me know that she was hungry."

"mother it's not really social anxiety [for her], it's only if [someone] cough[s] or sneezes[s], that's it."

<table>
<thead>
<tr>
<th>Severe symptoms upon re-infection</th>
<th>The Severity of COVID symptoms increases with recurrent infection. Re-infection with more severe symptoms may occur despite complete COVID vaccination.</th>
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<tbody>
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<td></td>
<td>&quot;She was fully vaccinated….she got it again and it was in January, she got really really bad high fever and all symptoms, everything came back, and she still has the taste and smell&quot;</td>
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<td></td>
<td>&quot;She got COVID again in January 8th, it affects more her asthma, made her asthma worse, and she had more joint pain and constant headache.&quot;</td>
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<td></td>
<td>&quot;I got COVID again and it was really strange from them and they give me the same treatment again&quot;</td>
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<td></td>
<td>&quot;After a week after this visit, my fever got very bad. After evaluation, they told me to stay in the hospital, and I stayed there for a week. Then I went home shortly, and then I came back&quot;</td>
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<tr>
<td></td>
<td>&quot;The day after Thanksgiving, I got the COVID again, and it was strange for them; they gave me again the same treatment and prescribed me steroids.&quot;</td>
</tr>
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</table>

| Worsened pre-existing conditions | Many participants have a history of other medical conditions. Some parents are confused |
|---------------------------------|---------------------------------------------------------------------------------
|                                  | "She got COVID again in January 8th, it affects more her asthma, made her asthma worse" |
|                                  | "at the beginning of September, I was sick with COVID for four months initially, I had a mild..." |
about whether some symptoms result from COVID or pre-existing medical conditions. COVID increases the pre-existing medical conditions' symptoms severity.

headache, and then I had a hard time to breath; They recommended to visit my oncology doctors because I have previously had cancer and I received B cell treatment that replete my B cells which this my antibodies, so I have no antibodies to fight against antibodies; I cannot create any antibodies"

"He has allergy to Amoxicillin and Formula, and he was diagnosed with Autism"

"He keeps speeding all the time, even 3 days or week without him setting….. he likes to sit by himself"

"The doctor wants him to get MRI for hydrocephalus, his head is above 100 percentile"

| Lack of insurance coverage and costly treatments | The health insurance for the COVID-19 pandemic does not cover most people. The medication prescribed by the doctor (antibiotics) was expensive, around $800, and was not covered by insurance. Most of the parents could not afford to buy the medication out-of-pocket. | "Each time we take the child to the hospital, the doctor prescribes antibiotics."

"The medication was about $800, It was a lot of amounts, and we couldn’t afford it." |

| Support systems utilized | Many parents mentioned similar things that they thought would have been beneficial to help them, their children, and the entire family during the patient’s infection and throughout the pandemic. The main type of aid | "…a support group, other parents that were actually going through the same thing that my daughter and I were going through…"

"…a lot of support from my family and the friends I have…"

"Soccer has been helping him a lot."

"He gets a lot of help at school from his teachers. He got a lot of support with that (mental health)…that positively affected him…helped him get caught up on grades." |
mentioned was support groups, with some parents going further and saying they would have wanted a support group for parents of children with COVID. Other supports mentioned that people relied on to get them through this tough time were friends/family, school/teachers, athletics, and technology. However, some parents said nothing would have made their experience easier and that it was something they had to get through. 

<table>
<thead>
<tr>
<th>Recovery and resilience</th>
<th>Wearing a mask everywhere, taking precautions even after having recovered from covid and continuing to isolate, anxiety, adjusting well, feeling good.</th>
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<td>&quot;I resorted to video game and internet, being connected to my friends there, so I didn’t feel too isolated.&quot;</td>
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<td>&quot;it's really just her. like, we don't wear a mask anymore, her brothers don't, but she still does&quot;</td>
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<td>&quot;He just has anxiety, like right after having covid but now he's doing well&quot;</td>
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<td></td>
<td>&quot;it's good, she's okay. she's just careful, trying to be careful&quot; &quot;Yes, in person, she's just wearing the mask every day&quot;</td>
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<td></td>
<td>&quot;We continue to wear a mask everywhere; they go to school, and she does play basketball without a mask, but we don't eat inside restaurants or go anywhere without a mask. the cases are going down, so I don't know when to put down your guard so yeah, she's pretty much doing all the things.&quot;</td>
</tr>
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<td></td>
<td>&quot;it's just that, I wouldn't go out as much, I really wasn't, I didn't go out a lot. I just stayed indoors, like school I had the option to go to class but I chose to stay home. Yeah, just isolating more, that's about it.&quot;</td>
</tr>
</tbody>
</table>
"it's kind of difficult because at the beginning he didn't want to go outside because he heard the news and everybody's saying if you contact people and they have the covid, they will get it again, so it was kind of difficult for him. I mean, for everybody."

"she's scared, she won't go near anyone who's coughing, she won't go near anyone who's sneezing. if she sees someone coughing or sneezing, she runs. it's not really social anxiety [for her], it's only if [someone] cough[s] or sneezes[s], that's it."

Themes derived from patients with Long-COVID (Table 1)

Table 1 reports the seven themes that were identified that relate to long-COVID patients: (1) social anxiety and depression, (2) post-traumatic stress disorder (PTSD)-like symptoms, (3) severe symptoms upon re-infection, (4) worsened pre-existing conditions, (5) lack of insurance coverage and costly treatments, (6) support systems utilized, and (7) recovery and resilience.

Child Theme 1: Social Anxiety and Depression

Starting with the theme of social anxiety and depression, we found that many participants reported mental health challenges such as anxiety, depression, irritability, and even hallucinations, but these symptoms were not ubiquitous, and a majority of these patients recovered with time. One specific example involved a girl who had been hospitalized for COVID-19 illness for less than one day. She shared the following experience as her daughter was recovering at home:

"Mom! Why are you crying?' Probably like 20 times a day she would say that. And I was like 'I'm not crying'. That night she came up and she was hysterical and she was brushing..."
stuff off of her and I was like 'what are you doing?' She's like 'there's ants or spiders crawling all over me'."

– Mother of a 11-year-old girl who had been hospitalized with COVID-19 illness

**Child Theme 2: Post-Traumatic Stress Disorder-Like Symptoms**

Some participants had more severe or long-lasting mental health symptoms that were similar to the symptoms of PTSD. This included severe anxiety or panic attacks triggered by hearing coughing, seeing people not wearing a mask, getting within six feet of strangers, and having a prolonged fear of re-infection. One mother described her daughter’s social anxiety as a result of her COVID-19 hospitalization and illness experience as follows:

"She's more afraid to go out in public. She doesn't really want to go out anymore because of [having COVID], since she had COVID two years ago."

– Mother of a 9-year-old girl who had been hospitalized with COVID-19 illness

**Child Theme 3: Severe Symptoms Upon Reinfection**

We also found that many of our participants had worsened symptoms upon COVID re-infection. After their primary infection, they often stated that the symptoms lasted longer and were more severe upon secondary or even tertiary infections; participants also reported to be fully vaccinated before being re-infected.

**Child Theme 4: Worsened Pre-existing Conditions**

Other participants with pre-existing conditions, such as asthma, reported that their conditions worsened during or after their COVID infection.

**Child Theme 5: Lack of Insurance Coverage and Costly Treatments**
Additionally, some participants reported having trouble securing health insurance to pay for medications prescribed to help treat COVID or its long-term effects, and the out-of-pocket costs were often unaffordable.

Child Theme 6: Support System Utilization

However, despite these hardships, we found a strong theme of resilience from both the parents of patients and the patients themselves to COVID infection and the pandemic in general. Many patients relied on support systems such as family, friends, sports/athletics, video games/electronics, and other sources to help them manage their COVID symptoms and life during the pandemic.

Child Theme 7: Recovery and Resiliency

Overall, this combination of resilience and support system utilization led to better recovery results, and many of our participants reported being fully recovered at the time of the interview. One mother of a 12-year-old boy recovering from long COVID said:

"He just has anxiety, like right after having covid but now he's doing well"

Themes derived from parents of children with long-COVID (Table 2)

Table 2 reports our findings that relate to the parents of children suffering from long-COVID symptoms. Like Table 1, Table 2 consists of three sections: theme name, theme description, and supporting quotes.
<table>
<thead>
<tr>
<th>Theme Name</th>
<th>Theme Description</th>
<th>Supporting Quote(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of COVID unknowns</td>
<td>Many parents described a sense of fear and apprehension due to COVID-19 being a new disease with many unknowns.</td>
<td>&quot;Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school.&quot;</td>
</tr>
<tr>
<td>Support systems utilized/needed</td>
<td>Parents discussed support systems that were utilized and ones they wish would have existed to help manage/deal with their children's COVID-19 infections.</td>
<td>&quot;...a lot of support from my family and the friends I have...&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;Soccer has been helping him a lot.&quot;</td>
</tr>
<tr>
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<td>&quot;He gets a lot of help at school from his teachers. He got a lot of support with that (mental health)...that positively affected him...helped him get caught up on grades.&quot;</td>
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<tr>
<td></td>
<td></td>
<td>&quot;...a support group, other parents that were actually going through the same thing that my daughter and I were going through.&quot;</td>
</tr>
<tr>
<td>Mixed messaging from health information sources</td>
<td>Over the course of the COVID-19 pandemic, as the situation evolved, sources sometimes released recommendations that were different or contradicted each other. This caused confusion amongst some of the parents interviewed.</td>
<td>&quot;At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. And I’m like &quot;well that’s what they are saying now that they only have to stay for 5 days&quot;.&quot;</td>
</tr>
<tr>
<td>School systems both helping and hurting</td>
<td>For some parents and their children suffering from COVID, their schools were helpful in aiding recovery.</td>
<td>&quot;Yeah, we are working on [his academic performance] now. There's a psychologist who just came in (to the school)...so they are working on him to see all about that, so we have not had the results yet.&quot;</td>
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Table 2. Themes relating to parents of children with Long-COVID
However, many parents expressed concerns that their children's schools were not doing enough to prevent COVID outbreaks and did not treat COVID as a serious concern.

"He gets a lot of help at school from his teachers. He got a lot of support with that (mental health)...that positively affected him...helped him get caught up on grades."

"At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. She’s afraid...She said 'my teacher was coughing one time' and she was so scared...Right now, if she could be in online school it would be better."

"Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school."

Four themes were identified that relate to parents of long-COVID patients: (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) support systems utilized and needed, and (4) school systems both helping and hurting during the COVID pandemic.

Parent Theme 1: Fear of COVID-19 Unknowns / Parent Theme 2: Mixed Messaging from Health Information Sources

For the first theme, fear of COVID unknowns, we found that many of the parents interviewed had a general fear regarding COVID, mainly revolving around its relative newness and the lack of concrete information that comes with a new infectious disease. This fear was often not eased by major sources of health information (e.g., the CDC, NIH, WHO) as the
information and recommendations being released by these different organizations were not always in agreement, causing further confusion and fear for parents. One mother stated:

"Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school."

"At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. And I’m like ‘well that’s what they are saying now that they only have to stay for 5 days."

Parent Theme 3: Support Systems Utilized and Needed / Parent Theme 4: School Systems Both Helping and Hurting During the Pandemic

Parents also felt as though school administrators were not doing enough to prevent outbreaks, and that they were not treating COVID with the appropriate level of concern or seriousness. On the other hand, parents also expressed gratitude towards school teachers for being considerate and helpful throughout the pandemic, providing support to students who missed school due to COVID infection. One consistent need expressed by the parents which would have been beneficial for them and their families was a parental support group in which they could discuss their issues and concerns with other parents of children with long COVID. Specifically, parents stated:

"He gets a lot of help at school from his teachers. He got a lot of support with his mental health. That positively affected him and helped him get caught up on grades."
"...a support group, other parents that were actually going through the same thing that my daughter and I were going through."

Discussion

The purpose of this qualitative study was to better understand and explore child/adolescent and parent/caregiver experiences with persistent COVID symptoms after serious illness that required hospitalization. Persistent COVID symptoms are still not well understood, especially in the pediatric population as children have been shown to have less severe illness requiring hospitalization versus adults. Seven themes that underscore the importance of mental health and well-being in COVID-19 illness recovery were revealed; (1) social anxiety and depression, (2) post-traumatic stress disorder like symptoms, as well as (3) severe symptoms upon re-infection, (4) worsening pre-existing conditions, (5) costly treatments and lack of insurance coverage, (6) support systems utilized, and (7) overall resilience and recovery were identified among patients. Four themes were identified relating specifically to the parents of long-COVID patients, including (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) schools being both a support system and a hindrance, and (4) specific support systems utilized and needed. These findings have important implications for children and families as we plan for post-pandemic recovery efforts.

Throughout our interviews, parents of children with long-COVID expressed an underlying sense of fear stemming from the fact that COVID was a newly emerging disease; at the start of the pandemic, little was known about how it would affect adults or children in the short- or long-term. Parents did not know what to expect in the days, weeks, months, or years after their child's initial COVID infection. Compounding this fear was that parents often felt dissatisfied with COVID guidance given by local, state, and federal health agencies. Indeed, an
internal review, ordered by CDC director Dr. Rochelle Walensky in April 2022 and released in September 2022, determined that the CDC was slow to release guidance and that it was often found to be confusing or overwhelming.13 This bared out in our findings here, and underscores that the CDC may not have done enough to assuage parental fears or provide adequate and timely information. However, in response to these shortcomings, the CDC has initiated an overhaul to its processes to be better prepared for future crises.13 Some of the changes made included streamlining the process for publication of data/findings, and the re-establishment of the Advisory Committee to the Director.13 Regardless, as children continue to become infected with SARS-CoV-2 it will be important to connect those families who experience persistent symptoms with physical and mental health recovery resources, both in medical and community environments.

A second major underlying cause of increased anxiety and stress among the parents interviewed was that insurance did not always cover COVID/long-COVID/MIS-C treatments. One mother described how her insurance company would not cover a medication prescribed for her daughter who was experiencing recurrent infections post-COVID. The out-of-pocket cost for this medication was approximately $800, a price the mother stated she could not afford. News media have reported patients having trouble getting their insurance companies to recognize long COVID as a covered illness or to pay for treatments related to their long symptoms.14 Future policy work could place pressure on insurance companies to recognize long COVID as a covered illness. The federal government has already taken steps toward this by listing long COVID as a disability under the Americans with Disabilities Act (ADA).15 However, this has not ensured that insurance companies must pay for long COVID treatments, so further legislation is needed.
Parents were not the only ones that experienced stress, fear, and anxiety related to COVID. Many parents described emotional and behavioral symptoms similar to post-traumatic stress disorder in their children such as avoidance, negative thinking/mood, and changes in their physical/emotional reactions in when in or around certain situations/environments/triggers.\textsuperscript{16} For example, one mother of a nine-year-old patient stated that, at the time of the interview, her daughter continues to have a fear response triggered by seeing or hearing people cough or sneeze, and that she continues to avoid being around people while in public. Evidence of PTSD-like symptoms is concerning as they could lead to future adverse outcomes in adulthood if not adequately treated by a professional.\textsuperscript{17} In response to this, the CDC and other pediatric organizations should consider COVID infection as a potential Adverse Childhood Event (ACE). An ACE is a “traumatic event that occurs before a child reaches the age of 18”\textsuperscript{18} and, according to the CDC, if a child experiences an ACE, it can have a tremendous lifelong negative impact on their health and increases their risk for violence, victimization, and perpetration.\textsuperscript{19} Recognizing COVID as an ACE can guide preventive and protective strategies that can be implemented to reduce the mental health impacts of COVID.\textsuperscript{20,21}

The classroom is one system through which policymakers and community stakeholders can have a direct and immediate impact on child health. Many parents we spoke with praised their children's schools for offering aid and resources to help their children recover post-COVID. This included teachers and other school staff offering additional time and attention to children who missed school due to their infection or the pandemic. Many parents reported initially that their children were doing worse in school at the start of the pandemic or right after their initial infection, but with time they were able to bring their grades back up. Some schools also offered resources to help deal with mental health issues, including hiring psychologists and additional
counselors so that children would have more opportunities to speak with a professional about mental health. However, parents also expressed disappointment in their school administrations. Some parents described school systems as not providing enough measures to protect their children from COVID infection. Others expressed that the school administration did not treat COVID with the seriousness they felt it deserved. At the start of the pandemic, many parents were satisfied with what schools were doing to prevent COVID spread, including masking and social distancing.22 According to a Pew Research Center report, 45% of parents surveyed said they were very satisfied with the steps their children’s school was taking to prevent the spread of the coronavirus.22 However, over the course of the pandemic, some states began to regulate the steps schools could take to limit COVID spread/exposure.23 One teacher said, “The precautions we put in place at the beginning of last year, things that were to help, to help reassure parents that we're doing everything we possibly can to keep our kids safe — we're not seeing that this year.”23 These changes left some parents feeling worried about their children’s safety. One mother, interviewed by The Texas Tribune, said “I am absolutely scared to death. I feel like a trapped animal that can't do anything to protect her babies. I would really prefer for [the school district] to offer virtual learning again.”23 These findings and remarks suggest that continued funding and resources can, and should support programs and interventions aimed at preventing COVID amongst school-aged children and to help students struggling with long COVID symptoms.24

Overall, most parents described the physical and mental state of their children as recovering either from the start of the pandemic or start of COVID infection. For instance, parents described grades, athletic ability, depression, anxiety, and social/behavioral issues as suffering initially but improving or ceasing over time. This pattern demonstrates resiliency in the
face of socioenvironmental stressors such as a global pandemic, but it has also been observed within other contexts such as war or natural disasters, especially when intervention programs are used to help children manage their thoughts, feelings, and reactions after a traumatic event. For example, a study involving students exposed to violence showed that those who underwent a Cognitive Behavioral Therapy (CBT) intervention program had significantly reduced symptoms of PTSD compared to the control. With effort and time, most of our patients interviewed made full recoveries. However, some continued to experience PTSD-like symptoms long after the initial infection. This process of recovery could have been hastened through CBT intervention program implementation. It is imperative that public health systems continue to care for children experiencing long COVID and long-term solutions and interventions be sought out and deployed.

**Study Limitations and Strengths**

There are study limitations that should be mentioned. As participants for this qualitative component were recruited from our main study, selection or participation bias may have occurred. There may also be limits to generalizability given we only sampled from one large pediatric healthcare system in one large urban area of the United States. Strengths of this study include a unique contribution to the literature, as there are few qualitative reports from around the world focused on the sustained impact of the COVID-19 pandemic among children and families. These studies are important as they can help inform the resources that will be necessary for health and community systems to support these children in their recovery.

**Conclusions**
A subset of children who were hospitalized with COVID-19 illness are experiencing a range of serious mental health impacts related to persistent COVID symptoms, namely PTSD and social anxiety. Parents are also experiencing related stressors as a result of seeking medical care and resources to support their child’s recovery. Clinical and public health support strategies should be developed to support these children and their families as they re-integrate in school, social and community activities.
References

1. Children and COVID-19:


**Standards for Reporting Qualitative Research (SRQR)**
http://www.equator-network.org/reporting-guidelines/srqr/

### Title and abstract

- **Title** - Concise description of the nature and topic of the study. Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended

- **Abstract** - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions

### Introduction

- **Problem formulation** - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement

- **Purpose or research question** - Purpose of the study and specific objectives or questions

### Methods

- **Qualitative approach and research paradigm** - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale

- **Researcher characteristics and reflexivity** - Researchers’ characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers’ characteristics and the research questions, approach, methods, results, and/or transferability

- **Context** - Setting/site and salient contextual factors; rationale

- **Sampling strategy** - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale

- **Ethical issues pertaining to human subjects** - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues

- **Data collection methods** - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale
**Data collection instruments and technologies** - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study

**Units of study** - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)

**Data processing** - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts

**Data analysis** - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale

**Techniques to enhance trustworthiness** - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale

**Results/findings**

**Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory

**Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings

**Discussion**

**Integration with prior work, implications, transferability, and contribution(s) to the field** - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field

**Limitations** - Trustworthiness and limitations of findings

**Other**

**Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed

**Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.*
The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:
# Persistent Symptoms and Conditions Among Children and Adolescents Hospitalized with COVID-19 Illness: A Qualitative Study

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<th>BMJ Open</th>
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<td>Date Submitted by the Author:</td>
<td>14-Apr-2023</td>
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<tr>
<td>Complete List of Authors:</td>
<td>Messiah, Sarah; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences; University of Texas Health Science Center, School of Public Health Francis, Jackson; The University of Texas Health Science Center at Houston Weerakoon, Sitara; The University of Texas Health Science Center at Houston, Mathew, M.; The University of Texas Health Science Center at Houston Shaikh, Sumbul; Children’s Health System of Texas Veeraswamy, Apurva ; Southern Methodist University Lozano, Alejandra; Children’s Health System of Texas He, Weiheg; The University of Texas Health Science Center at Houston Xie, Luyu; The University of Texas Health Science Center at Houston, ; Center for Pediatric Population Health Polavarapu, Dhatri; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences Ahmed, Nabila; University of Texas Health Science Center at Houston, Epidemiology, Human Genetics and Environmental Sciences Kahn, Jeffrey; The University of Texas Southwestern Medical Center</td>
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Persistent Symptoms and Conditions Among Children and Adolescents Hospitalized with COVID-19 Illness: A Qualitative Study

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Abstract

Objectives: There is limited in-depth research exploring persistent symptoms and conditions among children and adolescents who contracted COVID-19 illness that required hospitalization. The main objective of this study was to conduct qualitative interviews among families who had a child hospitalized with COVID-19 illness to elucidate their child’s physical, mental, and social health outcomes months after initial acute infection.

Design, Setting and Participants: A qualitative study that comprised of in-depth interviews among families with a child hospitalized with COVID-19 illness in one large urban US pediatric healthcare system. Parents (N=25) were recruited from an ongoing quantitative study to estimate the prevalence of long COVID in children hospitalized with COVID-19 illness. During in-depth interviews, parents were invited to describe their child’s post-COVID symptoms and experiences. Interviews were audiotaped, transcribed, and coded in NVivo.

Results: Seven themes were identified concerning the child’s prolonged COVID-19 experiences; (1) post-traumatic stress disorder, (2) social anxiety, (3) severe symptoms upon re-infection, (4) worsened pre-existing conditions, (5) lack of insurance coverage for costly treatments, (6) access and utilization of support systems, and (7) overall resilience and recovery. Four parent-specific themes were identified; (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) schools being both a support system and a hindrance, and (4) desire for, and access to support systems.

Conclusions: A subset of children who were hospitalized with COVID-19 illness are experiencing a range of serious mental health impacts related to persistent COVID symptoms.
Clinical and public health support strategies should be developed to support these children and their families as they re-integrate in school, social and community activities.

**Strengths and Limitations:**

- Qualitative, in-depth interviews captured the unique experiences of long COVID among a sample of children who were hospitalized with COVID-19 illness.

- Experiences of long-COVID were captured among a vulnerable pediatric sample.

- Because of the limited sample size, generalizability to larger populations, and other demographics may not be possible.

- Causal inferences cannot be made between patient-reported long COVID-related symptoms and the COVID infection itself.
Introduction

As of September 15, 2022, there have been almost 14.7 million documented COVID-19 cases in the United States pediatric population.[1] Data shows that the majority of COVID-19 cases in children and adolescents are asymptomatic and do not typically require hospitalization.[1] However, the Centers for Disease Control and Prevention (CDC) reports that over 1,200 children and adolescents through age 18 years have died from COVID-19 illness.[2] A small proportion of children with COVID-19 illness are at risk for developing a novel Kawasaki-like disease called multisystem inflammatory syndrome in children (MIS-C).[3] As of September 25, 2022, there have been 8,862 MIS-C cases reported in children, most with a positive SARS-CoV-2 test result.[4]

Irrespective of hospitalization status, some children infected with SARS-CoV-2 can develop symptoms or complications that last for several months, but are typically less severe than those in adults.[5,6] Symptoms that persist after acute COVID-19 illness are called various names; long COVID, post-acute sequelae of SARS-CoV-2 [PASC], post-COVID-19 syndrome, long-haul COVID, and chronic COVID syndrome.[5] To date, long COVID has been shown to consist of over 200 symptoms, including fatigue, sleep disturbance, concentration difficulties, loss of appetite, muscle or joint pain, pulmonary fibrosis, myocardial dysfunction, and mental health conditions.[5,7,8,9]

At this time, there is no standardized definition of long COVID-19 in adults, and the quality of evidence is still developing.[10,11] In children, there is a general lack of data regarding long COVID, especially among those diagnosed with MIS-C versus those not diagnosed with MIS-C, and in children less than 11 years old.[10,12,13] It is important to assess the incidence and prevalence of long COVID in children as it may impact their social, emotional,
mental, and physical health, as well as academic performance, all of which have the potential to impact a child’s quality of life even beyond the pediatric years.[14] Yet, there are very few studies that have qualitatively, or assessed in-depth the social and mental impacts of COVID-19 illness in children. [8,9,10] This is especially true for those children most severely impacted by COVID-19 illness coming from diverse backgrounds. Therefore, the aim of this study was to conduct qualitative interviews among families who had a child who was hospitalized with COVID-19 illness among a sample of ethnically and socioeconomically diverse children. It was hypothesized that parents would identify new symptoms and experiences from the standard CDC list currently available.

Methods

We report here results from an exploratory qualitative study using semi-structured in-depth interviews. The study is reported following the Standards for Reporting Qualitative Research framework (SRQR).[15]

Participants

Using convenience and volunteer sampling, a total of 25 parents were recruited between March 2021 and April 2022. Participants were eligible if they had previously reported in an ongoing quantitative study conducted during the same time period that their child was experiencing long-COVID or post-COVID conditions and had consented to participate in an in-depth interview at a later date. The UTHealth Committee for the Protection of Human Subjects approved all aspects of the current study (study number HSC-SPH-20-1133).

Study Recruitment
As part of a larger quantitative study among a large sample of children hospitalized for COVID-19 illness, parents were asked if they would be interested in also participating in an in-depth interview at a later time. Among those parents who expressed interest in participation, research team members called a maximum of three times to schedule an interview. Participants provided informed and written consent prior to taking part in the interview. All qualitative interviews that are reported here took place between January and April, 2022.

Data Collection

Interviews were conducted by five graduate-level qualitative research-trained team members [SS, JF, WH, AL, AV], with AL conducting all Spanish interviews. A semi-structured interview guide was developed, informed by our quantitative study findings, the literature, study aims, and the research team’s expertise (See Table 1). The guide was iteratively reviewed throughout the study. Interviews were conducted on the telephone, audio recorded, and later transcribed by an external provider. Interviews lasted between 10 and 32 min (mean average = 21 min). Data collection was terminated once no further categories were identified. All participants received a $25 gift card as compensation for their time and participation.

Data Analysis

Data were analyzed using an inductive coding approach. Initially, the first authors [JF, SM] read and re-read all transcripts while taking reflective notes. Line-by-line coding of the first five transcripts was conducted to create an initial list of codes, which were reviewed and refined with the research team through critical dialogue. All transcripts were imported to NVivo Pro v12 and codes were created to systemically capture interesting aspects of the data across the entire dataset. The initial list of codes was further extended and refined throughout the entire coding
process. To promote study rigor and maintain a connection to the project, 25 transcripts were second coded by the 5 co-authors [JF, SW, DP, NA, AL]. Themes were identified based on the existing coding and organized into themes. The final set of themes was refined through discussions with the research team.

**Patient and public involvement**

Patients and the public were not involved in this research’s design, conduct, reporting or dissemination plans.

**Results**

Of the 25 pediatric patients, 13 (52%) were female, 15 were White/Caucasian, 6 were Black/African American, and 4 were another race. Furthermore, 14 were Hispanic and 11 were non-Hispanic. Pediatric patients ranged in age from 4 months old to 18 years old at age of initial COVID-19 diagnosis. The parents/caregivers of the 25 pediatric patients were interviewed by phone, of which 2 were conducted in Spanish. After conducting our interviews and performing the subsequent analysis, we derived the results shown below in Tables 1 and 2. The themes identified fall into two broad categories; themes that relate to the pediatric patient who experienced the COVID-19 illness (Table 1), and themes that relate to the parents of patients, and their experiences caring for a child with long-COVID (Table 2). All themes derived from both parent and pediatric patient experiences are visually presented in Figure 1.
<table>
<thead>
<tr>
<th>Theme Name</th>
<th>Theme Description</th>
<th>Supporting Quote(s)</th>
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| Social anxiety and depression      | COVID infection were related to mental health issues in children such as anxiety, depression, and hallucinations, but not all were affected. Recovery is common, though some still experience persistent symptoms. | "In school, if someone is talking loudly or making more noise, she gets anxiety."
"She is afraid of separation from me [the mother]."
"Doesn't want to go out, cries and says just get something for me. I don't want to go out."
"He just has anxiety, like right after having covid but now he's doing well"

| PTSD-like symptoms                 | All patients reported fully recovering from any behavioral changes; changes included tiring easily, hearing and seeing things that weren't there, loss of appetite, speech delay, some children still fear going out in public. | "Mom! Why are you crying?" Probably like 20 times a day...And I was like 'I'm not crying'. That night she was hysterical, and she was brushing stuff off her...She's like 'there's spiders crawling all over me'. The next day she was still hearing crying...she kept hearing a noise and she said she saw a monster and was so terrified. I've never seen her so horrified and just hearing and seeing things. She was like 'I was frozen, I couldn't move because there was a monster.' You know she never had a fever...I knew that she was probably having hallucinations...I've never seen her like that before and it was terrifying."

"It's kind of difficult because at the beginning he didn't want to go outside because he heard the news and everybody's saying if you contact people and they have the covid, they will get it again.

"She's more afraid to go out in public. She doesn't really want to go out anymore because of [having COVID], since she had COVID two years ago."

"She didn't fully get back to herself probably until like maybe that last week of December...Because you know at first I would have to wake her up to eat but once she started staying up, and she was more alert, and then she would come to me to let me know that she was hungry."

"It's not really social anxiety [for her], it's only if [someone] cough[s] or sneezes[s], that's it."

| Severe symptoms upon re-infection  | The Severity of COVID symptoms increases with recurrent infection. Re-infection with more severe symptoms may occur despite complete COVID vaccination.                                                                 | "She was fully vaccinated...she got it again in January, she got really bad high fever and all symptoms, everything came back, and she still has the taste and smell."
"She got COVID again January 8th, it affects more her asthma, made her asthma worse, and she had more joint pain and constant headache."

"I got COVID again and it was really strange and they give me the same treatment again."
<table>
<thead>
<tr>
<th>Worsened pre-existing conditions</th>
<th>Many participants have a history of other medical conditions. Some parents are confused about whether some symptoms result from COVID or pre-existing medical conditions. COVID increases the pre-existing medical conditions' symptoms severity.</th>
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<tr>
<td></td>
<td>&quot;She got COVID again in January 8th, it affects more her asthma, made her asthma worse&quot;</td>
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<td>&quot;I was sick with COVID for four months initially, I had a mild headache, and then I had a hard time to breath; I have previously had cancer and I received B cell treatment...so I have no antibodies to fight, I cannot create any antibodies&quot;</td>
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<td>&quot;The doctor wants him to get MRI for hydrocephalus, his head is above 100 percentile&quot;</td>
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<td>Lack of insurance coverage and costly treatments</td>
<td>Health insurance doesn't cover many peoples COVID infections. Medications prescribed for COVID were not covered, and most parents couldn't afford them.</td>
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<tr>
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<td>&quot;Each time we take the child to the hospital, the doctor prescribes antibiotics.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;The medication was about $800, It was a lot of amounts, and we couldn't afford it.&quot;</td>
</tr>
<tr>
<td>Support systems utilized</td>
<td>Parents mentioned that support groups for parents of children with COVID would have been helpful during their child's infection and the pandemic. Forms of support utilized included friends/family, school/teachers, athletics, and technology. Though some said nothing would have made it their experience easier.</td>
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<td>&quot;...a support group, other parents that were actually going through the same thing that my daughter and I were going through...&quot;</td>
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<td>&quot;...a lot of support from my family and the friends I have...&quot;</td>
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<td>&quot;He gets a lot of help at school from his teachers. He got a lot of support with mental health...that positively affected him...helped him get caught up on grades.&quot;</td>
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<td>&quot;I resorted to video game and internet, being connected to my friends there, so I didn’t feel too isolated.&quot;</td>
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<td>&quot;Soccer has been helping him a lot.&quot;</td>
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<tr>
<td>Recovery and resilience</td>
<td>Wearing a mask everywhere, taking precautions even after having recovered from covid and continuing to isolate, adjusting well, feeling good.</td>
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<td>&quot;It's good, she's okay. she's just careful, trying to be careful&quot; &quot;Yes, in person, she's just wearing the mask every day&quot;</td>
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<td>&quot;We continue to wear a mask everywhere; they go to school, and she does play basketball without a mask, but we don't eat inside restaurants or go anywhere without a mask. the cases are going down, so I don't know when to put down your guard.”</td>
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<tr>
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<td>&quot;It's just that, I wouldn't go out as much. I just stayed indoors, like school, I had the option to go to class but I chose to stay home. Yeah, just isolating more, that's about it.&quot;</td>
</tr>
</tbody>
</table>
Themes derived from patients with Long-COVID (Table 1)

Table 1 reports the seven themes that were identified that relate to long-COVID patients: (1) social anxiety and depression, (2) post-traumatic stress disorder (PTSD)-like symptoms, (3) severe symptoms upon re-infection, (4) worsened pre-existing conditions, (5) lack of insurance coverage and costly treatments, (6) support systems utilized, and (7) recovery and resilience.

Child Theme 1: Social Anxiety and Depression

Starting with the theme of social anxiety and depression, we found that many participants reported mental health challenges such as anxiety, depression, irritability, and even hallucinations, but these symptoms were not ubiquitous, and a majority of these patients recovered with time. One specific example involved a girl who had been hospitalized for COVID-19 illness for less than one day. She shared the following experience as her daughter was recovering at home:

"'Mom! Why are you crying?' Probably like 20 times a day she would say that. And I was like 'I'm not crying'. That night she came up and she was hysterical and she was brushing stuff off of her and I was like 'what are you doing?' She's like 'there's ants or spiders crawling all over me'."

– Mother of a 11-year-old girl who had been hospitalized with COVID-19 illness

Child Theme 2: Post-Traumatic Stress Disorder-Like Symptoms

Some participants had more severe or long-lasting mental health symptoms that were similar to the symptoms of PTSD. This included severe anxiety or panic attacks triggered by hearing coughing, seeing people not wearing a mask, getting within six feet of strangers, and
having a prolonged fear of re-infection. One mother described her daughter’s social anxiety as a result of her COVID-19 hospitalization and illness experience as follows:

"She’s more afraid to go out in public. She doesn’t really want to go out anymore because of [having COVID], since she had COVID two years ago."

– Mother of a 9-year-old girl who had been hospitalized with COVID-19 illness

Child Theme 3: Severe Symptoms Upon Reinfection

We also found that many of our participants had worsened symptoms upon COVID re-infection. After their primary infection, they often stated that the symptoms lasted longer and were more severe upon secondary or even tertiary infections; participants also reported to be fully vaccinated before being re-infected.

Child Theme 4: Worsened Pre-existing Conditions

Other participants with pre-existing conditions, such as asthma, reported that their conditions worsened during or after their COVID infection.

Child Theme 5: Lack of Insurance Coverage and Costly Treatments

Additionally, some participants reported having trouble securing health insurance to pay for medications prescribed to help treat COVID or its long-term effects, and the out-of-pocket costs were often unaffordable.

Child Theme 6: Support System Utilization

However, despite these hardships, we found a strong theme of resilience from both the parents of patients and the patients themselves to COVID infection and the pandemic in general. Many patients relied on support systems such as family, friends, sports/athletics, video
games/electronics, and other sources to help them manage their COVID symptoms and life during the pandemic.

**Child Theme 7: Recovery and Resiliency**

Overall, this combination of resilience and support system utilization led to better recovery results, and many of our participants reported being fully recovered at the time of the interview. One mother of a 12-year-old boy recovering from long COVID said:

"He just has anxiety, like right after having covid but now he's doing well"

**Themes derived from parents of children with long-COVID (Table 2)**

Table 2 reports our findings that relate to the parents of children suffering from long-COVID symptoms. Like Table 1, Table 2 consists of three sections: theme name, theme description, and supporting quotes.

<table>
<thead>
<tr>
<th>Theme Name</th>
<th>Theme Description</th>
<th>Supporting Quote(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of COVID unknowns</td>
<td>Many parents described a sense of fear and apprehension due to COVID-19 being a new disease with many unknowns.</td>
<td>&quot;Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school.&quot;</td>
</tr>
<tr>
<td>Support systems utilized/needed</td>
<td>Parents discussed support systems that were utilized and ones they wish would have existed to help manage/deal with their children's COVID-19 infections.</td>
<td>&quot;...a lot of support from my family and the friends I have...&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;Soccer has been helping him a lot.&quot;</td>
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<tr>
<td></td>
<td></td>
<td>&quot;He gets a lot of help at school from his teachers. He got a lot of support with that (mental health)...that positively affected him...helped him get caught up on grades.&quot;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;...a support group, other parents that were actually going through the same thing that my daughter and I were going through.&quot;</td>
</tr>
</tbody>
</table>
### Mixed messaging from health information sources

Over the course of the COVID-19 pandemic, as the situation evolved, sources sometimes released recommendations that were different or contradicted each other. This caused confusion amongst some of the parents interviewed.

"At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. And I’m like “well that’s what they are saying now that they only have to stay for 5 days”.”

### School systems both helping and hurting

For some parents and their children suffering from COVID, their schools were helpful in aiding recovery. However, many parents expressed concerns that their children’s schools were not doing enough to prevent COVID outbreaks and did not treat COVID as a serious concern.

"Yeah, we are working on [his academic performance] now. There’s a psychologist who just came in (to the school)...so they are working on him to see all about that, so we have not had the results yet."

"He gets a lot of help at school from his teachers. He got a lot of support with that (mental health)...that positively affected him...helped him get caught up on grades."

"At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. She’s afraid...She said 'my teacher was coughing one time' and she was so scared...Right now, if she could be in online school it would be better."

"Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school."

---

Four themes were identified that relate to parents of long-COVID patients: (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) support systems utilized and needed, and (4) school systems both helping and hurting during the COVID pandemic.

**Parent Theme 1: Fear of COVID-19 Unknowns / Parent Theme 2: Mixed Messaging from Health Information Sources**
For the first theme, fear of COVID unknowns, we found that many of the parents interviewed had a general fear regarding COVID, mainly revolving around its relative newness and the lack of concrete information that comes with a new infectious disease. This fear was often not eased by major sources of health information (e.g., the CDC, NIH, WHO) as the information and recommendations being released by these different organizations were not always in agreement, causing further confusion and fear for parents. One mother stated:

"Because I felt like with the outbreak at the school, I wanted to see more in terms of what they were doing to prevent another outbreak at the school. So, I changed her to a different school."

"At school a lot of the kids were sick and she was afraid because they just keep them [at home in isolation] for 5 days and then they have to go back [to school] and she’s like, ‘well sometimes they come back and they’re still coughing and have fever. And I’m like "well that’s what they are saying now that they only have to stay for 5 days.""

Parent Theme 3: Support Systems Utilized and Needed / Parent Theme 4: School Systems Both Helping and Hurting During the Pandemic

Parents also felt as though school administrators were not doing enough to prevent outbreaks, and that they were not treating COVID with the appropriate level of concern or seriousness. On the other hand, parents also expressed gratitude towards school teachers for being considerate and helpful throughout the pandemic, providing support to students who missed school due to COVID infection. One consistent need expressed by the parents which would have been beneficial for them and their families was a parental support group in which
they could discuss their issues and concerns with other parents of children with long COVID. Specifically, parents stated:

"He gets a lot of help at school from his teachers. He got a lot of support with his mental health. That positively affected him and helped him get caught up on grades."

"...a support group, other parents that were actually going through the same thing that my daughter and I were going through."

Discussion

The purpose of this qualitative study was to better understand and explore child/adolescent and parent/caregiver experiences with persistent COVID symptoms after serious illness that required hospitalization. Persistent COVID symptoms are still not well understood, especially in the pediatric population as children have been shown to have less severe illness requiring hospitalization versus adults. Seven themes that underscore the importance of mental health and well-being in COVID-19 illness recovery were revealed; (1) social anxiety and depression, (2) post-traumatic stress disorder like symptoms, as well as (3) severe symptoms upon re-infection, (4) worsening pre-existing conditions, (5) costly treatments and lack of insurance coverage, (6) support systems utilized, and (7) overall resilience and recovery were identified among patients. Four themes were identified relating specifically to the parents of long-COVID patients, including (1) fear of COVID unknowns, (2) mixed messaging from health information sources, (3) schools being both a support system and a hindrance, and (4) specific support systems utilized and needed. These findings have important implications for children and families as we plan for post-pandemic recovery efforts.
Throughout our interviews, parents of children with long-COVID expressed an underlying sense of fear stemming from the fact that COVID was a newly emerging disease; at the start of the pandemic, little was known about how it would affect adults or children in the short- or long-term. Parents did not know what to expect in the days, weeks, months, or years after their child's initial COVID infection. Compounding this fear was that parents often felt dissatisfied with COVID guidance given by local, state, and federal health agencies. Indeed, an internal review, ordered by previous CDC director Dr. Rochelle Walensky in April 2022 and released in September 2022, determined that the CDC was slow to release guidance and that it was often found to be confusing or overwhelming.[16] This bared out in our findings here, and underscores that the CDC may not have done enough to assuage parental fears or provide adequate and timely information. However, in response to these shortcomings, the CDC has initiated an overhaul to its processes to be better prepared for future crises.[16] Some of the changes made included streamlining the process for publication of data/findings, and the re-establishment of the Advisory Committee to the Director.[16] Regardless, as children continue to become infected with SARS-CoV-2 it will be important to connect those families who experience persistent symptoms with physical and mental health recovery resources, both in medical and community environments.

A second major underlying cause of increased anxiety and stress among the parents interviewed was that insurance did not always cover COVID/long-COVID/MIS-C treatments. One mother described how her insurance company would not cover a medication prescribed for her daughter who was experiencing recurrent infections post-COVID. The out-of-pocket cost for this medication was approximately $800, a price the mother stated she could not afford. News media have reported patients having trouble getting their insurance companies to recognize long
COVID as a covered illness or to pay for treatments related to their long symptoms.[17] Future policy work could place pressure on insurance companies to recognize long COVID as a covered illness. The federal government has already taken steps toward this by listing long COVID as a disability under the Americans with Disabilities Act (ADA).[18] However, this has not ensured that insurance companies must pay for long COVID treatments, so further legislation is needed.

Parents were not the only ones that experienced stress, fear, and anxiety related to COVID. Many parents described emotional and behavioral symptoms similar to post-traumatic stress disorder in their children such as avoidance, negative thinking/mood, and changes in their physical/emotional reactions in when in or around certain situations/environments/triggers.[19] For example, one mother of a nine-year-old patient stated that, at the time of the interview, her daughter continues to have a fear response triggered by seeing or hearing people cough or sneeze, and that she continues to avoid being around people while in public. Evidence of PTSD-like symptoms is concerning as they could lead to future adverse outcomes in adulthood if not adequately treated by a professional.[20] In response to this, the CDC and other pediatric organizations should consider COVID infection as a potential Adverse Childhood Event (ACE). An ACE is a “traumatic event that occurs before a child reaches the age of 18”[21] and, according to the CDC, if a child experiences an ACE, it can have a tremendous lifelong negative impact on their health and increases their risk for violence, victimization, and perpetration.[22] Recognizing COVID as an ACE can guide preventive and protective strategies that can be implemented to reduce the mental health impacts of COVID.[23,24]

The classroom is one system through which policymakers and community stakeholders can have a direct and immediate impact on child health. Many parents we spoke with praised their children's schools for offering aid and resources to help their children recover post-COVID.
This included teachers and other school staff offering additional time and attention to children who missed school due to their infection or the pandemic. Many parents reported initially that their children were doing worse in school at the start of the pandemic or right after their initial infection, but with time they were able to bring their grades back up. Some schools also offered resources to help deal with mental health issues, including hiring psychologists and additional counselors so that children would have more opportunities to speak with a professional about mental health. However, parents also expressed disappointment in their school administrations. Some parents described school systems as not providing enough measures to protect their children from COVID infection. Others expressed that the school administration did not treat COVID with the seriousness they felt it deserved. At the start of the pandemic, many parents were satisfied with what schools were doing to prevent COVID spread, including masking and social distancing.[25] According to a Pew Research Center report, 45% of parents surveyed said they were very satisfied with the steps their children’s school was taking to prevent the spread of the coronavirus.[25] However, over the course of the pandemic, some states began to regulate the steps schools could take to limit COVID spread/exposure.[26] One teacher said, “The precautions we put in place at the beginning of last year, things that were to help, to help reassure parents that we're doing everything we possibly can to keep our kids safe — we're not seeing that this year.”[26] These changes left some parents feeling worried about their children’s safety. One mother, interviewed by The Texas Tribune, said “I am absolutely scared to death. I feel like a trapped animal that can't do anything to protect her babies. I would really prefer for [the school district] to offer virtual learning again.”[26] These findings and remarks suggest that continued funding and resources can, and should support programs and interventions aimed at preventing
COVID amongst school-aged children and to help students struggling with long COVID symptoms.[27]

Overall, most parents described the physical and mental state of their children as recovering either from the start of the pandemic or start of COVID infection. For instance, parents described grades, athletic ability, depression, anxiety, and social/behavioral issues as suffering initially but improving or ceasing over time. This pattern demonstrates resiliency in the face of socioenvironmental stressors such as a global pandemic, but it has also been observed within other contexts such as war or natural disasters, especially when intervention programs are used to help children manage their thoughts, feelings, and reactions after a traumatic event.[20] For example, a study involving students exposed to violence showed that those who underwent a Cognitive Behavioral Therapy (CBT) intervention program had significantly reduced symptoms of PTSD compared to the control.[28] With effort and time, most of our patients interviewed made full recoveries. However, some continued to experience PTSD-like symptoms long after the initial infection. This process of recovery could have been hastened through CBT intervention program implementation.[20] It is imperative that public health systems continue to care for children experiencing long COVID and long-term solutions and interventions be sought out and deployed.

Study Limitations and Strengths

There are study limitations that should be mentioned. As participants for this qualitative component were recruited from our main study, selection or participation bias may have occurred. There may also be limits to generalizability given we only sampled from one large pediatric healthcare system in one large urban area of the United States. It is imperative that future research consider the cultural context of long-COVID in other geographical regions of the
world. Strengths of this study include a unique contribution to the literature, as there are few qualitative reports from around the world focused on the sustained impact of the COVID-19 pandemic among children and families. These studies are important as they can help inform the resources that will be necessary for health and community systems to support these children in their recovery.

**Conclusions**

A subset of children who were hospitalized with COVID-19 illness are experiencing a range of serious mental health impacts related to persistent COVID symptoms, namely PTSD and social anxiety. Parents are also experiencing related stressors as a result of seeking medical care and resources to support their child’s recovery. Clinical and public health support strategies should be developed to support these children and their families as they re-integrate in school, social and community activities.

**Running Title:** Persistent COVID in Children

**Word Count:** 3583

**Number of Tables:** 2

**Number of Figures:** 1

**Conflicts of Interest:** The authors declare no conflicts of interest.

**Financial Support/Funding Statement:** None

**Ethical Approval:** The UTHealth Committee for the Protection of Human Subjects approved all aspects of the current study (study number HSC-SPH-20-1133).

**Data sharing statement:** The data and codes generated during and/or analyzed during the current study are available from the first author(s) upon reasonable request.

**Author Contributions:** SM and JF conceptualized and designed the study, drafted the initial
manuscript, and carried out the initial analyses. JK and LX provided clinical guidance, critically reviewed the manuscript for important intellectual content, and revised the manuscript. SM, MSM, and JF coordinated and supervised data acquisition, and reviewed and revised the manuscript. SS, JF, WH, AL, and AV conducted all qualitative interviews. JF, SW, DP, NA, and AL conducted the qualitative thematic analysis. SM supervised data analyses, interpretation of results, reviewed and revised the manuscript. All authors read and approved the final version.

**Key Words:** children, long COVID, persistent COVID, adolescents, illness
References

1. Children and COVID-19:


16. CDC moving forward summary report | about | CDC.


27. U.S. Department of Education. Supporting students during the COVID-19 pandemic: Maximizing in-person learning and implementing effective practices for students in quarantine
Figure Legend

Figure 1: Visual representation of thematic analysis results from both pediatric patient and parent/caregiver interviews.
Pediatric Patients

Experiences with long COVID-19

Parents/Caregivers

Lack of insurance coverage and costly treatments
The health insurance for the COVID-19 pandemic does not cover most people.

Support systems utilized
Systems that would have been beneficial to help patients and their families during infection and throughout the pandemic.

Support systems utilized
Systems utilized and ones they wish would have existed to help manage their children's COVID-19 infection.

Recovery and resilience
Patients described adjusting well after having recovered.

Fear of COVID unknowns
Parents described a sense of fear and apprehension due to COVID-19 being a new disease.

Mixed messaging from health information sources
Over the course of the pandemic, sources sometimes released recommendations that were different or contradicted each other.

School systems both helping and hurting
For some parents and their children, schools were helpful in aiding recovery; however, many parents expressed concerns.

Worsened pre-existing conditions
Many patients have a history of other medical conditions.

PTSD-like symptoms
All patients reported fully recovering from any behavioral changes; some patients still fear going out in public.

Social anxiety & depression
Mental health issues among patients during the pandemic

Severe symptoms upon re-infection
The severity of COVID-19 symptoms increased with recurrent infection.

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# Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

<table>
<thead>
<tr>
<th>Title and abstract</th>
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<tbody>
<tr>
<td><strong>Title</strong> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</td>
</tr>
<tr>
<td><strong>Abstract</strong> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</td>
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<tr>
<th>Introduction</th>
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<tr>
<td><strong>Problem formulation</strong> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</td>
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<td><strong>Purpose or research question</strong> - Purpose of the study and specific objectives or questions</td>
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<tr>
<td><strong>Qualitative approach and research paradigm</strong> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</td>
</tr>
<tr>
<td><strong>Researcher characteristics and reflexivity</strong> - Researchers’ characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers’ characteristics and the research questions, approach, methods, results, and/or transferability</td>
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<td><strong>Context</strong> - Setting/site and salient contextual factors; rationale**</td>
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<td><strong>Sampling strategy</strong> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</td>
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<td><strong>Ethical issues pertaining to human subjects</strong> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</td>
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<td><strong>Data collection methods</strong> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</td>
</tr>
<tr>
<td><strong>Data collection instruments and technologies</strong> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study</td>
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<tr>
<td><strong>Units of study</strong> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)</td>
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<tr>
<td><strong>Data processing</strong> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts</td>
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<td><strong>Data analysis</strong> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**</td>
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<tr>
<td><strong>Techniques to enhance trustworthiness</strong> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**</td>
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**Results/findings**

| **Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 9-19 |
| **Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 9-19 |

**Discussion**

| **Integration with prior work, implications, transferability, and contribution(s) to the field** - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 19-24 |
| **Limitations** - Trustworthiness and limitations of findings | |

**Other**

| **Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 2 |
| **Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 2 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.*
**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.**

Reference: