

The Burden of COVID-19 on Caregivers of Children with Suspected Genetic Conditions: A Therapeutic Odyssey

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ABSTRACT

Aims: Children with disabilities and rare or undiagnosed conditions and their families have faced numerous hardships of living during the COVID-19 pandemic. For those with undiagnosed conditions, the diagnostic odyssey can be long, expensive, and marked by uncertainty. We, therefore, sought to understand whether and how COVID-19 impacted the trajectory of children's care.

Methods: We conducted semi-structured qualitative interviews with 25 caregivers who, prior to the pandemic, were on a diagnostic odyssey for their children.

Results: Most caregivers did not report any interruptions to their child's diagnostic odyssey. The greatest impact was access to therapy services, including the suspension or loss of their child's in-person therapeutic care and difficulties with virtual therapies. This therapy gap caused caregivers to fear that their children were not making progress.

Conclusion: Although much has been written about the challenges of diagnostic odysseys for children and their families, this study illustrates the importance of expanding the focus of these studies to include *therapeutic* odysseys. Because therapeutic odysseys continue regardless of whether diagnoses are made, future research should investigate how to support caregivers through children's therapies within and outside of the COVID-19 context.

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The COVID-19 pandemic has highlighted inequities in the social and health systems of the United States, exacerbating vulnerabilities in access to care for particular groups of people. Across the world, individuals with disabilities and rare or undiagnosed conditions (RUDs) are not only at increased risk of dying from COVID-19 infection, but

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surveys conducted early in the pandemic revealed that people with disabilities or RUDs and their families were facing numerous hardships of living during a pandemic (Halley et al., 2021). One notable hardship included the suspension of recommended medical care (Cacioppo et al., 2021; Dickinson & Yates, 2020; Halley et al., 2021; Willner et al., 2020). Multiple factors influenced this suspension early in the pandemic, such as patient and family fear of exposure, barriers to access healthcare and therapeutic services, shortage of personal protective equipment (PPE) and other resources, and hospitals shifting priorities to care for, or prepare to care for, patients with COVID-19. Further, caregivers of those with disabilities and chronic conditions were at greater risk of suffering from mental health stressors and poor social support than caregivers of children without disabilities (Al van Tilburg et al., 2020; Cacioppo et al., 2021; Navas et al., 2022; Rogers et al., 2021; Willner et al., 2020).

For children with undiagnosed conditions, the search for a diagnosis, or diagnostic odyssey, can be long, expensive, and marked by uncertainty. Beginning with the identification of symptoms by patients or caregivers, the diagnostic odyssey can last years as patients may see multiple specialists, receive incorrect diagnoses, and undergo unnecessary medical procedures before obtaining the correct diagnosis (Carmichael et al., 2015; Sawyer et al. 2016). Before the COVID-19 pandemic, parents of children on a diagnostic odyssey have described delays and “agonizingly long periods” between appointments, tests, and learning results (Miller 2021, p. 218; Simon et al., 2022). While getting a diagnosis can provide some with access to services, social support networks, medical management plans, as well as closure and improved quality of life (Miller 2021; Fraiman & Wojcik, 2021), a genetic diagnosis does not always mean that the odyssey ends for families (Rosell et al., 2016). Instead, families may embark on therapeutic odysseys, which Brosco (2018) describes as a “search for anything that will help their child walk, talk, run, play, learn to read and write, and wonder and search for answers.” Given strains on healthcare systems due to COVID-19, we, therefore, sought to understand how both caregivers’ and their children’s daily lives had been impacted by the early stages of the COVID-19 pandemic, and, in turn, how these impacts affected the trajectory of children’s care.

Methods

Participants

This qualitative interview study was performed within a larger study called North Carolina Clinical Genomic Evaluation by Next-generation Exome Sequencing 2 (NCGENES 2). NCGENES 2 is evaluating the impact of early implementation of exome sequencing on the diagnostic odyssey of children with suspected genetic conditions (Staley et al., 2021). Interviewees were 25 caregivers of children enrolled in NCGENES 2 (Trial Registration NCT03548779) who, prior to the pandemic, were on a diagnostic odyssey for their children. All had their first appointment in the pediatric genetics or neurology clinic of University of North Carolina Hospital (Chapel Hill, NC) or Mission Health (Asheville, NC) between November 2018 and December 2019. To be eligible for the COVID-19 interview study, caregivers had to have completed all NCGENES 2 study activities. Upon entry into NCGENES 2, caregivers were asked to provide demographic data that are also used in the present study.

Table 1. Demographic characteristics of interviewees ($N = 25$).

| Variable | | Frequency | Percentage |
|-------------------|---------------------------|-----------|------------|
| Gender | Man | 2 | 8 |
| | Woman | 23 | 92 |
| Race/Ethnicity | Asian | 2 | 8 |
| | Black or African American | 4 | 16 |
| | Hispanic or Latinx | 2 | 8 |
| | White | 16 | 64 |
| | Did not report | 1 | 4 |
| Income | \$5,000–\$14,999 | 4 | 16 |
| | \$15,000–\$24,999 | 4 | 16 |
| | \$25,000–\$39,999 | 4 | 16 |
| | \$40,000–\$69,999 | 3 | 12 |
| | \$70,000–\$99,999 | 3 | 12 |
| | \$100,000 or above | 7 | 28 |
| Partner Status | Single or widowed | 6 | 24 |
| | Partnered or married | 19 | 76 |
| Child's Insurance | Medicaid | 11 | 44 |
| | Military | 2 | 8 |
| | Private | 9 | 36 |
| | Did not report | 3 | 12 |

We mailed letters to 40 caregivers to introduce them to the interview study and invite them to participate. The letter stated that we were interested in caregivers' perspectives on how COVID-19 had impacted their child's care, access to resources, and search for a diagnosis. We also said that we were interested in how the pandemic has impacted their lives more generally. Caregivers then received a follow up email or phone call a week later to learn if they would like to participate. Caregivers received a \$50 gift card after completing the interview.

This study was determined to be exempt by the University of North Carolina at Chapel Hill Institutional Review Board and was carried out in accordance with the Declaration of Helsinki.

Table 1 reports the demographic characteristics of the 25 interviewed caregivers. Almost all were the parents of children enrolled in NCGENES 2; one was the child's grandparent and primary guardian. The 25 interviewees included: 23 women and 2 men; 16 who identified as non-Hispanic white, 4 who identified as Black, 2 who identified as Asian, 2 who identified as Hispanic, and 1 who did not report. Almost half of the participants (48%) reported a household income of less than \$40,000, and most caregivers were partnered (76%). The average age of the interviewees' focal child was 4.6 years ($SD = 3.1$). With respect to the child's medical insurance, 11 were insured through Medicaid, 9 were insured privately, and 2 were insured through the military. Three participants did not report the child's medical insurance provider.

Interview Guide

To address whether and how the COVID-19 pandemic impacted diagnostic odysseys, the authors developed an interview guide (Supplementary Appendix A) which included open-ended questions on the pandemic's effects on medical care and services. The interview guide also included questions on schooling, finances, familial relationships, and psychosocial health of family members to address how COVID-19 had impacted

Table 2. Summary of key themes.

Key themes

- Most diagnostic odysseys were not interrupted by COVID-19.
 - Some interviewees reported delays in medical care that did not affect their child's diagnostic odyssey, resulting from canceled appointments or clinic COVID-19 testing policies.
 - Even though they did not impact diagnostic odysseys, clinic visitor policies limiting the number of people who could accompany patients increased the burden of seeking medical care for families.
 - Transitions to telemedicine eliminated some of the burden of seeking medical care in terms of finding childcare to abide by visitor policies or traveling long distances to appointments.
 - Access to therapies was significantly impacted by COVID-19.
 - Therapeutic services were canceled by providers or stopped because of school closures. Some interviewees chose to cancel or not initiate therapies because of fears of COVID-19 exposure.
 - Transitions to virtual therapy proved difficult for almost all interviewees due to caregivers' lack of training and adequate technology to facilitate therapy sessions at home.
 - Due to the lack of access to in-person therapies and difficulties with virtual therapies, many caregivers feared their children were not making progress during COVID-19.
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families' daily lives. Additionally, caregivers were asked whether their child had received a diagnosis for their symptoms and, if so, when the diagnosis was received.

Procedure

Between August and November of 2020, two interviewers (MW and RJC) conducted semi-structured telephone interviews with the 25 caregivers. The two interviewers conducted the informed consent process, and participants provided verbal consent to participate prior to the interview commencing. Interviews averaged 30 minutes in length and were audio recorded and later transcribed for analysis.

Data Analysis

Interview transcripts were read in their entirety by a subset of authors, who then met several times to identify emerging themes and develop an analytic memo template to analyze each transcript. Analytic memos were used to identify how each theme was addressed in the interviews, summarize key information related to each theme, identify representative quotes, and note initial impressions of how themes relate to each other (Groenewald 2008; Patel et al, 2016). An initial subset of transcripts were memoed, at which point team members met again to revise the template. Transcripts were then divided among team members for memoing. Each drafted memo and the corresponding transcript was reviewed by another team member. When necessary, clarifications, changes, or additions identified by the reviewer were discussed among team members to finalize the memos. The lead author summarized themes across all finalized memos for review by team members and returned to the transcripts to confirm the context of illustrative quotes to be used to represent each theme in the manuscript. Specifically, data were analyzed to identify themes related to the impact of COVID-19 on the medical care and therapies of children in NCGENES 2 (see Table 2). By medical care, we refer to care provided by physicians and nurses, such as pediatricians, dentists, ophthalmologists, medical geneticists, and other specialty providers. By therapies, we mean developmental interventions such as physical, occupational, behavioral, and speech therapy.

Results

Medical Care during COVID-19

Interruptions to the Diagnostic Odyssey

Among the twenty-five interviewees, only two caregivers reported interruptions to their child's diagnostic odyssey due to the COVID-19 pandemic. The first caregiver (ID: 1) noted that, prior to the pandemic, her child's physician was pursuing an ADHD diagnosis. However, their request that the child's teachers fill out evaluation forms was impeded by school closures, stating, "Then everything got shut down, so we really didn't have a chance to follow through with that." Having matriculated to the next grade level, the caregiver planned to wait until the child's new teachers became familiar with the child before again requesting the evaluations. The second caregiver (ID: 2) was pursuing an explanation for her child's hearing loss, noting that her daughter "had pretty regular appointments. We were finally starting to get some answers on some stuff beforehand," prior to the start of the pandemic. However, her daughter's appointments were all canceled due to the pandemic and had yet to be rescheduled at the time of the interview (October 2020). She struggled with this delay, saying it made her "feel like my kid got kicked to the curb."

Delays in Medical Care

Other caregivers reported delays in getting medical care or devices for their children, rather than delays affecting their child's diagnostic odyssey. For example, one interviewee (ID: 3) stated that her son was prescribed corrective eyeglasses before the pandemic began but they never arrived. During the pandemic, in order to obtain a second prescription, her son was required to schedule a new ophthalmology appointment and repeat the entire process. The mother commented that she feels the delay in getting eyeglasses "interfered with his school[ing]." Another parent (ID: 4) described the delay in her son's dental work, which was scheduled for early 2020 but was postponed until fall of that year. Although the delay did not impact his diagnostic odyssey, the mother noted that it did cause her son a lot of pain.

Changes to clinic policies during the pandemic also delayed medical care. One caregiver (ID: 5) decided to cancel her son's hearing test due to the clinic's COVID-19 testing policy. The clinic required COVID-19 testing before the appointment, which meant a three to four-hour drive to the medical office for the COVID-19 test and a return trip to the appointment after receiving the test results. This parent could not travel that far multiple times.

The rest of the caregivers did not report that their child's diagnostic odysseys or medical care were impacted. Some children already received diagnoses before COVID-19. But even for those who had not received a diagnosis, medical appointments were typically not interrupted as most were waiting for their regularly scheduled 6- or 12-month follow-up appointment. For example, when asked if there were any delays in medical appointments because of COVID-19, one caregiver (ID: 6) noted that there were no delays because the medical appointments "fell right in the time when people were actually able to start going to appointments again."

Impact of COVID-19 Visitor Policies

Although most interviewees reported that their child's medical appointments generally stayed on track, clinics with visitor policies that limited the number of people who could accompany a patient to their visits increased the burden of seeking medical care for caregivers and their families. One caregiver (ID: 7) said:

We're seeing the same doctors ... We only see [the doctor] every six months. [COVID-19] hasn't really affected anything ... The hardest part is not being able to take the other two kids [to the appointments]. And trying to find someone to babysit the kids when we have an appointment or this or that. It's really hard.

Similarly, another caregiver (ID: 8), whose partner is in the military, noted the challenges of seeking emergency medical care for one child while also being the sole caregiver for multiple children. She said:

Last time I went to an appointment because of [an emergency], and the hospital did not allow me to go inside because I brought too many kids. They said you should bring only one kid. So I said, 'Ok, I understand, but how can I do that?'

While some caregivers struggled with finding childcare, others reported that COVID-19 visitor policies were burdensome because only one caregiver could attend the child's medical appointments. One caregiver (ID: 9) noted "only one of us could go. Normally, both parents go to all of [our child's medical appointments]." When asked her thoughts on the policy, she said:

I understand it because of health reasons. I understand, but it's hard because I was trying to record the doctor. It was just inconvenient to not be able to have both parents there when we're both active in our child's medical care.

Another caregiver (ID: 10) discussed the stress of waiting alone while her child had surgery. She stated that, "It was really hard having to be the only person there. My husband wasn't allowed to come, so it was difficult. It was difficult just emotionally being the only one there, yeah, just feeling alone ..."

Transitions to Telemedicine

Conversely, the transition to telemedicine eliminated some of the burdens of seeking medical care during COVID-19. Caregivers cited some benefits of telemedicine appointments, including not having to worry about finding childcare or traveling long distances to appointments. However, some caregivers were frustrated by the inability of providers to physically examine the child and because of language barriers exacerbated by telemedicine. For example, one caregiver (ID: 11) said she prefers in-person appointments because "in person, they could see her, and I can explain better. I mean, I don't speak that much English. I understand, but some words, I get confused to say. So I prefer in person. I can express myself better."

Therapeutic Care and Services during COVID-19

Interruptions to Therapeutic Care

While medical care and appointments were generally not interrupted by COVID-19, all caregivers who needed to access in-person therapies for their child, including physical,

occupational, speech, behavioral, and psychotherapy, faced difficulties doing so. Some families received in-home care that was stopped by the service provider because of the pandemic. One caregiver (ID: 8) said of her son that “usually the physical therapist is coming to our house, but because of COVID, they stopped home visiting. So after that, he never got physical therapy and speech therapy.” For children who received therapies in school, school closures also impacted families’ abilities to get therapies. Once schools closed due to the pandemic, one mother (ID: 12) noted that “there was really no type of therapies that were provided.” While her daughter typically received speech, occupational, and physical therapy through her school, school closures meant that “pretty much all those services stopped...” In addition, school openings in the fall of 2020 did not guarantee renewed access to in-school therapies, as exemplified by one caregiver (ID: 13) who was met with resistance from school administration when seeking physical therapy services for her daughter. The mother stated that school administration informed her that they were “far more concerned with academics, so [her daughter] probably wouldn’t get much PT.” For children who receive these interventions for free in school, parents were left contemplating whether and how they might afford to pay for the services on their own. The mother above worried: “[I]f we have to pay for this ourselves, how do we do that?”

For caregivers whose children received therapies in their own homes, many chose to either cancel or not initiate therapies as they worked to find a balance between their child’s need for developmental interventions and risk of exposure to COVID-19. For example, one caregiver (ID: 7) said:

We actually cut all therapy off at the beginning of COVID because I didn’t feel comfortable having three different people that go to how many other people’s houses a day come to ours as well. And [our child] doesn’t have an immune disease... But if we get a standard 24-hour stomach bug, we end up in the hospital... So I would rather just – I was just scared, and I was trying to prevent as much as I could.

Adding difficulty to her decision to cut off all therapy was the loss of social support as she described her child’s physical therapist as “literally like family.” Similarly, one mother (ID: 14) with access to in-home Applied Behavior Analysis (ABA) therapy for her child with autism stated that after a few weeks of therapy, the therapist “went on vacation in one of the places that was pretty high on numbers of COVID. So I decided to [take] two weeks off from services.” At the time of the interview (October 2020), “he still hasn’t received any ABA services that are being consistent” because of rotations in staffing. Caregivers also delayed starting therapies because of COVID-19. For instance, one did not start occupational therapy for her son because the therapy would not be in-person. She (ID: 4) said, “Our pediatrician did say [my son] probably would benefit from OT therapy, but... she just said... he needed in-person [occupational therapy], so we just kind of put that on hold for now.”

Transitions to Virtual Therapy

Given the reduction and sometimes complete elimination of in-person appointments, many families restarted their child’s therapy services virtually. Nearly every interviewee who participated in virtual therapies struggled with such services, with one of the most common difficulties being the lack of resources provided to caregivers as the virtual

setting required them to participate in therapy appointments in a different way. Caregivers often felt they were not properly trained to support virtual therapy providers, which included difficulty motivating their children to perform for them as they would with a trained therapist. One caregiver (ID: 12) noted that “it’s very, very challenging to do a virtual visit for physical therapy. Because really, it’s the physical therapist telling us what we need to do for [my daughter], and... she works better with her therapist directly than Mom and Dad trying to do it.” The same caregiver noted that the difficulty of virtual therapy was compounded by having to work from home, saying, “My husband and I are already working from home, and we’re having to take care of the kids too. We’re tag-teaming them. But then we had to add on having these therapy sessions ... So it was just very, very challenging.” Even for those caregivers who did feel comfortable conducting therapies with their children, the process was still extremely stressful. For example, one interviewee (ID: 2) described herself as “hands-on” and “more comfortable than most people doing teletherapy,” however:

It does get overwhelming. I mean, you’re trying to nitpick everything. And then I feel like I’m – I guess because I’m her mom, I feel myself maybe getting more aggravated with her because I want her to just listen ... I found my patience ran out – I guess you could say – and I don’t like that. I don’t like that feeling towards my own kid, getting stressed at her when it’s something she can’t handle, and it’s definitely stressful.

Similarly, another (ID: 15) commented on the difficulty of conducting therapy with her young child, noting the therapy is “awkward for both of us.” She elaborated, saying:

For me, I have to constantly be getting and kind of moving the [device] screen. [The therapists] do like seeing him get up and run around and stuff, so I have to be moving constantly. And then they can’t always see what I’m doing with him. So then we’ll complete a task, and they’re like ‘Can you try that again?’ Or, ‘I didn’t see that. Your screen was moved.’ Or [my son] has almost no tolerance to sit there. I’ll have either my phone or my computer on, and I’m trying to do therapy, and he will get upset. And he’ll either cry, or he’ll run away...

Another challenge caregivers faced was a lack of adequate technology to facilitate therapy sessions, such as one caregiver (ID: 6) who said: “We do FaceTime or Zoom, and they instruct me on what to do ... It can get a little frustrating because I’m trying to hold the phone and help her ...” Similarly, another caregiver (ID: 16) noted that “It’s just kind of hard doing it from your phone. And I mean, if there was a way I could put it on my TV or something, it might be a little easier for me.”

Impact of Gap in Therapeutic Care

As a result of this gap in therapy services for those who did not have access to therapy and for those in virtual therapy, many parents feared that their children were not making hoped for progress. One caregiver (ID: 13) said, “I’ve missed [our physical therapist] every week. When she would be telling me what to do, and I’m like ‘I don’t think I’m doing this right.’ I’m like ‘I wish you were here to move her legs.’ ... I’m afraid that [my child is] not making the progress she would have made if we had been in person.” Concerned over her daughter’s development and an inability to initiate ABA therapy services since the pandemic began, another caregiver (ID: 11) said: “I need help [from ABA therapy] with her because she’s growing up, but she’s growing up and getting

worse. I mean, her behavior is getting worse every day... I mean, before COVID, she was getting stressed already because of her behavior. But with the COVID, [it is] more complicated.” She was also worried about her daughter’s progress in terms of speech therapy and had to, like many caregivers, make a difficult choice about whether and when to resume in-person therapy. They stopped virtual speech therapy, feeling it was unsuccessful, and decided to restart with in-person speech therapy once the office opened back up even with worries about contracting COVID-19. She (ID: 11) said, “I’ve been taking her every [week]. I mean, my husband said, ‘She’s going to get sick.’ I was like ‘I know, but she needs the speech too.’ I mean, she’s very, very speech delayed. So we have to take the risk.”

Discussion

In this interview study with caregivers of children with undiagnosed conditions, we sought to understand how families’ lives had been impacted by the early stages of the COVID-19 pandemic, and, in turn, how these impacts affected each child’s diagnostic odyssey. Most caregivers did not report any interruptions to their child’s diagnostic odyssey. This finding aligns with Campbell et al. (2022) who found no significant change in diagnostic rates in a genetics clinic in the ten months before and after COVID-19. The authors attributed this to a successful shift to telemedicine appointments. Yet in a survey conducted from April to June of 2020, Halley et al. (2021) found that those with rare and undiagnosed conditions faced delays in and additional challenges to being on a diagnostic odyssey because of COVID-19. These mixed results point to the need for additional longitudinal research on this topic.

While we did not find interruptions to children’s diagnostic odysseys, families did report difficulties obtaining medical care for family members. These difficulties were most often related to early COVID-19 policies, which restricted access to medical facilities. COVID-19 testing policies requiring multiple trips to clinics increased the burden of seeking medical care for families who lived in rural areas or far from medical centers. In addition, visitor policies limiting the number of caregivers and family members who could attend medical appointments early in the pandemic placed considerable strains on single-parent caregivers, caregivers with multiple children, and caregivers with limited access to childcare or to healthcare facilities. Restrictions on the number of people who could attend appointments also prevented some caregivers who were actively involved in their child’s care from attending appointments and engaging with the medical team. These findings are consistent with previous work on COVID-19 visitation policies and illuminate the critical importance of developing such policies in coordination with patients and their families to minimize disruptions in needed care (Andrist et al., 2020; Halley et al., 2021; Jaswaney et al., 2022).

Instead of interruptions to the diagnostic odyssey, we found that the greatest impact described by caregivers in this study was access to therapy services. While caregivers did discuss challenges in maintaining regular medical appointments during the pandemic, participants were most concerned with the suspension or loss of their child’s therapeutic care and the potential negative impacts on their daily lives and the development of their children with disabilities or RUDs. These findings are consistent with

surveys conducted during the early stages of the pandemic that found that respondents had concerns about the progress of children with disabilities or RUDs being lost during the pandemic because of school closings and lack of access to therapies or other supports (Dickinson & Yates, 2020). In fact, in one survey focusing on parents of children with physical disabilities, the most frequently cited concern among parents was lack of appropriate quality therapies during the pandemic (Cacioppo et al., 2021).

While prior research has pointed to the benefits of transitioning to telehealth as a way of enabling access to appropriate therapies during the pandemic (Alonazi, 2021), our findings reveal the complexity of such transitions. Caregivers did describe benefits of not having to travel or find childcare for virtual appointments, which can have positive impacts especially for single parents or those who live in rural areas far from medical centers. However, caregivers in our study also described the stresses of insufficient training, language and communication issues, inadequate technological resources, and physical space limitations that caused difficulties during virtual therapy appointments, which align with previous literature (Camden & Silva, 2021; Wittmeier et al., 2022). These stressors of virtual therapies are similar to the problems that were highlighted by popular press and research on virtual schooling (Garbe et al., 2020; Tully, 2021), which have implications for health equity (Crawford & Serhal, 2020) and the mental health of caregivers (Al van Tilburg et al., 2020; Cacioppo et al., 2021; Rogers et al., 2021; Willner et al., 2020). They also highlight the fragility of the therapy system even beyond the context of the pandemic. Caregivers have traditionally been expected to support their child's progress between formal therapy appointments (Almasri et al., 2018; Gibbs & Toth-Cohen, 2011; Kokorelias et al., 2019). However, the transition to virtual therapy early in the COVID-19 pandemic reveals that caregivers may not always be fully capacitated for this role. This finding has important implications for practice. While there are many benefits of telehealth visits, therapists should be aware that parents may find the transition to virtual appointments difficult and need training in how to facilitate therapy at home. Such training would be useful regardless of whether therapies are conducted virtually or in person since caregivers are typically expected to support exercises in between appointments. Increased support for caregivers in this role can both help children's progress and may prevent caregivers from blaming themselves for any perceived lack of developmental progress within and beyond the pandemic.

The finding that interviewees were most concerned by difficulties with therapy services also illustrates the importance of focusing not just on diagnostic odysseys but *therapeutic* odysseys within and outside of the context of the pandemic. In an interview study of parents of children with intellectual disabilities or developmental delays, Childerhose et al. (2021) call for a reframing of the diagnostic odyssey as one part of the broader therapeutic odyssey to help children thrive. Finding a diagnosis may be a way for caregivers to obtain therapeutic services for their children. In this way, the diagnosis represents the means to better therapeutic services or treatment for symptoms, and thus caregivers see the therapeutic odyssey as equally or more important than finding a diagnosis itself (Childerhose et al., 2021). Similarly, Brosco (2018) argues that parents are less interested in the name of a condition than with interventions that help maximize their child's functioning. The focus of researchers and clinicians on the diagnostic odyssey, including in our current study, may not fully account for the needs,

desires, and difficulties families face within the broader therapeutic odyssey. Because therapeutic odysseys continue regardless of whether diagnoses are made, future research should investigate how to support caregivers through children's therapies within and outside of the COVID-19 context, especially for those who may not be able to address any therapy gaps with monetary resources.

Limitations

As a sub-study of the larger NCGENES 2 clinical trial, this study's pool of potential interviewees was limited to participants who had already completed all NCGENES 2 study elements to limit any interruptions to the clinical trial. As such, this study did not capture the views of caregivers of children who had not yet been seen by pediatric specialists and, as a result, may have had differing experiences of the impacts of COVID-19 on the diagnostic or therapeutic odyssey. In addition, the phasic nature of the pandemic, as well as the evolution of its impact on geographic areas and demographic groups, means that these observations represent a "snapshot" of a potentially highly variable experience. As the pandemic remains ongoing, this limitation illustrates the need for continued, longitudinal research on how both the diagnostic and therapeutic odyssey have been impacted throughout the course of the pandemic.

Conclusion

Caregivers of children with undiagnosed conditions did not report interruptions to the diagnostic odyssey due to the COVID-19 pandemic. However, access to therapies was significantly impacted during COVID-19, including through difficulties with virtual therapy. These findings reinforce the need for health care practitioners, researchers, and policy makers to address the larger therapeutic odyssey for children with undiagnosed conditions and their families and to equip them with the social and emotional support, training, technology, and financial resources needed to navigate an odyssey that is challenging both within and beyond the context of the COVID-19 pandemic.

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Data availability statement

Due to the nature of this research, participants of this study did not consent to their data to be shared publicly, so supporting data is not available.

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