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Original Article

Parent and Adolescent Perspectives on the Impact of COVID on the Care of Seriously Ill Children

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Abstract

Context. Few studies have explored the impact of the Coronavirus Pandemic (COVID-19) on the care of seriously ill children which may be especially affected due to the child's vulnerability, complexity of care, and high reliance on hospital-based care.

Objective. To explore parental and adolescent perspectives on the impact of COVID-19 on care of seriously children.

Methods. We recruited a convenience sample of families of seriously ill children between September and December 2020. The study involved a semi-structured interview through Zoom followed by an online sociodemographic survey. Interviews were transcribed and coded using the constant comparison method. The sample intended to represent diversity in child age and diagnoses, and family sociodemographic characteristics.

Results. Sixty-four families were approached; 29 enrolled (response rate 45%), including 30 parents and three AYAs. Most parents and AYAs identified as white (62%). Some families reported new financial hardships, with 17.2% having difficulty paying bills after March 2020 compared to 6.9% before. Emerging themes from interviews included additional roles parents managed due to cancelled services or shifting to telehealth, increased isolation, high emotional distress due increased in-home demands, uncertainty, and visitor restrictions in medical facilities, and benefits and challenges to telehealth. One positive outcome was the use of a hybrid care model whereby families choose telehealth appointments and in-person services, when necessary.

Conclusion. Families caring for seriously ill children during COVID-19 face increased challenges. Health systems should consider long-term telehealth/in-person hybrid care models that have potential to improve access to and satisfaction with care. J Pain Symptom Manage 2022;63:52–60.

Key Words

COVID-19, children with serious illnesses, telehealth

Key Message

This article provides unique perspectives and experiences from seriously ill AYAs and parents caring for children with serious illnesses during COVID-19. We observed a negative impact on parent mental health as well as preferences for an in-person/virtual hybrid care model.

Introduction

The Coronavirus Pandemic (COVID-19) has affected daily life across the world, and this may be accentuated in families caring for seriously ill children.[1,2] Families have faced increased material hardships including housing and food insecurities and access to safe child care as a result of COVID-19.[3,4]

Abbreviations: AYA, adolescent and young adult; DFCI, dana-farber cancer institute, BCH, Boston children's hospital.

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Adverse outcomes observed in otherwise healthy children following the social isolation recommended by the CDC guidelines include delay in access to care, decreased physical activity, increased emotional distress, and increased domestic violence in the home.[5−8,10] While current literature describes substantial effects of COVID-19 on children's daily life and parental health,[10−13,16] few studies have assessed the impact of COVID-19 on caring for children with serious illnesses.

Children with serious illnesses represent a small percentage of the pediatric population yet they may be particularly vulnerable to adverse outcomes from COVID-19 due to underlying conditions and treatments such as immunosuppressive therapy.[18,1915] Routine challenges caregivers of seriously ill children face may also be compounded by additional considerations such as complex care coordination,[20] high reliance on hospital-based services and medical technology,[17] worries related to the child's enhanced vulnerabilities[21] and maintaining routine care such as disease directed therapies, school-based therapies, and home nursing for activities of daily living support.[9,14,15,22] In addition, certain hospital-based or rehabilitation services cannot feasibly occur at home or through telehealth.[23] Consequently, the burden on parent caregivers has likely increased as they have become the "mediums" through which care is assessed and provided.[24] However, there has been no formal study of the impact of COVID-19 on caring for seriously ill children.

At the time this manuscript is being written, cases in Massachusetts and the United States are waning,[25,26] most children remain unvaccinated and seriously ill children continue to be among the most vulnerable.[27] Thus, to address this research gap, we conducted a mixed-methods study to explore the impact of COVID-19 on the care of seriously ill children. Our goal was to learn about families' and adolescents' experiences related to care and impact on parent caregivers.

Methods

Study Design and Setting

This mixed-methods study was conducted at Dana-Farber Cancer Institute (DFCI) and Boston Children's Hospital (BCH) in Boston, Massachusetts from September 2020 through December 2020. A series of in-depth interviews were performed using Zoom videoconference platform. Following the interview, a brief online socio-demographic survey was emailed to participants to gather self-reported data. The study was approved by the institutional review board at DFCI and verbal informed consent was obtained at the beginning of each interview.

Selection Criteria

Eligible participants included parents of seriously ill children, adolescents or young adults (AYAs, <30 years old) and AYAs (<>15 and 30 years old) receiving care at DFCI and/or BCH. For this study, we defined "having a serious illness" as either being followed by the palliative care services, or having previously participated, actively participating, or being potentially eligible for any of the ongoing studies of the Pediatric Palliative Care (PPC) research team. Exclusion criteria included any parent(s) whose child had died, or who was unable to read, write, and speak English, and parents of or AYAs who had been off disease-directed treatment and in remission for greater than six months. Potentially eligible participants were screened from the daily pediatric oncology clinic list and active PPC patient lists at DFCI and BCH. Subjects who had participated or were currently participating in one of the team's studies, were only approached if they had allowed future contact on their informed consent form. The primary provider or PPC team was given the opportunity via email to decline permission to contact the patient/parents.

Semi-structured Interview

A qualitative semi-structured interview was conducted and audio recorded through Zoom. Interview guides were created de novo and refined through soliciting feedback from PPC investigators and clinicians. The guide included questions about the significance of COVID-19 on the child's medical care, experience with telehealth visits, and other challenges faced during this time. Two versions of the interview guide were created, Parent and AYA; the AYA guide was used whenever an AYA participated in the interview, whether alone or with a parent.

Follow-up Brief Survey

A brief 28-item REDCap (Research Electronic Data Capture)[28,29] survey was sent to participants through an email link upon completion of the semi-structured interview to obtain self-reported socio-demographics including age, gender, race, ethnicity and zip code, among others.

Analysis

Analysis of interviews included coding themes and assessing transcripts to understand the data.[30] Answers to the open-ended questions were transcribed verbatim removing any personal identifiers; transcripts were not returned to participants for review. Analysis was conducted with the qualitative research software NVivo (Mac R1). Data coding was performed by two members of the research team (GH and LB) who were trained by the research manager experienced in coding. Data coders also received ongoing feedback from study investigators. Coding was inductive using a

constructivist research paradigm and started with initial open coding followed by further iterations to fit the data using the constant comparison method, until theoretical saturation was reached.[31] Thematic codes and sub-codes were then developed and redefined to be more inclusive of the data. Cross-coding comparison was assessed in NVivo using a Kappa statistic to determine inter-rater agreement. Differences were solved by reflective discussion.

Survey data were collected and managed using REDCap. Median distance to medical facility was determined by zip code. Medium household income was estimated by geocoding using census data through 2015 and zip code.[32]

Results

Sixty-four families were sent the invitation letter of which 29 enrolled, 17 were unable to be contacted after three calls, six did not show for interview appointments and were unable to be contacted thereafter, six declined, and six had a change in eligibility from time of screening to approach for an overall response rate of 45%. Thirty parents across 28 families participated, two AYAs completed the interview with their parents (ages 15 and 22), and one AYA completed it independently (age 20). Twenty-nine out of thirty parents and all three AYAs completed the sociodemographic questionnaire. Table 1 shows the main characteristics of enrolled subjects. Most participants identified as white (62%). Some families faced financial hardships with 17.2% reporting "much" or "a great deal" of difficulty paying bills after March 2020 compared to 6.9% before. The median distance families travelled from home to DFCI/BCH was 34 miles (four−712 mi; IQR 19 −75mi), including five families who travelled over 100 miles. Among the parents interviewed, 45% had a child with a primary oncologic diagnosis compared to 55% whose child had a non-oncologic primary diagnosis (Table 1).

Table 1
Participant Demographics and Clinical Characteristics

	Child $N = 29$ No. (%)	Parents $N = 29$ No. (%)
Gender		
Female	15 (52)	26 (89)
Age in years, median (range)	12 (<1−28)	41 (29−71)
Race		
Asian,	2 (7)	2 (7)
Black or African American	2 (7)	2 (7)
White	19 (65)	18 (62)
Other	6 (21)	7 (24)
Ethnicity		
Non-Hispanic or Latino	26 (89)	26 (89)
Hispanic or Latino	3 (11)	3 (11)
Median household income	$70,000 ($29k−$135k; IQR $50−98,000)	
Median distance to DFCI/BCH by zip code	34 mi (4−712 mi; IQR 18−76mi)	
Primary Diagnosis		
Non-oncology		16 (55.1)
Cardiac condition		1 (3.4)
Hematologic condition		1 (3.4)
Neurologic condition		13 (44.8)
Renal disease		1 (3.4)
Oncology		13 (44.9)
Prior PPC Involvement = yes		19 (66)
Prior enrolment in PPC study = yes		15 (52)

The cross-coding comparison demonstrated an overall Kappa statistic of 0.77 showing a high percent agreement between independent data coders (GH and LB). The three most common themes used when coding the transcripts were changes in care, challenges and benefits to telehealth, and impact on parents (Table 2).

Changes in Care

Most AYAs and parents identified some element of change in their care or providing care for their child. This ranged from change in type of clinical encounter (in-person vs. virtual telehealth) (n = 18) and/or temporary pause of home services such as physical, occupational and speech therapies, and home nursing (n = 9). Eight families shared the child experienced a delay in care which included delay in clinic visits, delay in receiving necessary medical equipment or change in medication and three families shared a scheduled surgery was postponed. A few families also delayed appointments they felt were not "absolutely necessary" such as primary care and other routine visits. Six families shared challenges they faced with travel to and from medical facilities. For example, three families who rely on public transportation and ride shares stated they were nervous to use these services. One family cancelled an appointment as a result. Two families discussed impact on travel from outside of the state and the challenges in dealing with different state guidelines (Table 2). Among families who reported no change in their child's care (n = 11), 90% had a child with a primary oncologic diagnosis. These children continued to receive cancer-directed therapies in person. Comparatively, among families who reported a significant change in their child's home care (n = 13), 77% had a child with a non-oncologic primary diagnosis.

Key challenges reported by parents regarding their children's care included less availability of supplies needed to take care of their children (n = 7), feeling more burdened with their child's care by taking on more caregiving roles (n = 10), feeling isolated during hospital admissions and clinic visits due visitor restrictions in medical facilities (n = 10) and struggling to find safe childcare options for their other children (n = 10).

Table 2
Descriptive Quotes

Theme	Code	Descriptive Quote
Changes in Care	Changes to ome are (n = 16)	We called off – we cancelled all of his caregivers, so we'd have caregivers in the house for most of the day and night... – school was cancelled for a while. I think that's when they went remote for the first few months. . .it was kind of up to us, to my wife and myself, to provide care. -ParentNonOnc[a]
	Changes in institutional policy (n = 14)	I think that's the biggest change, for me, is that only one parent is allowed. So, I feel like that puts a lot more burden on the one parent. Before, both of us could go in and one of us could take a break and go down to the cafeteria or take a walk. But now, whoever goes in with him, they're just with him the whole time. -ParentOnc[b]
		I don't really feel 100 percent a part of his treatment and what's going on, . . .in the beginning, . . . I'd drive him to the door and then go find something to do in the city for a few hours. Now [my wife] knows the route down, so she goes on her own. -ParentOnc
		And everything takes a long time, so I was in that clinic like for four hours just with my daughter and I with – worried out of my mind but . . . my husband couldn't be there and there was almost nobody there. . . it was like a ghost town there because of the pandemic, people working remote. So you don't even see like another friendly face there, like another family waiting. It was really bizarre. So that's kind of how this first really started hitting me that this was going to be much different this time. –ParentOnc
		The other challenge I had was – it really actually boiled down to the rules of the hospital, with regards to, if I had an appointment for my child, then I had to figure out what to do with my other son. And my husband has to go to work, so then he's missing work because I can't take one with me. It's limited. And his age, it doesn't matter. So, that was sort of challenging right there. -ParentNonOnc
	Change in type of clinical encounter (n = 20)	So we have tons of outpatient appointments, and a lot of the appointments it's mostly just kind of checking with us and make sure – kind of try to figure out what's going on because [our child's] totally dependent on us. So a lot of the appointment actually was great because we didn't have to come in, we could just do it virtually, which I think is beneficial. -ParentNonOnc
	Parents taking on additional roles (n = 10)	I mean, he had counselors, and he had friends, and he had teachers, and a lot of others who were bearing the brunt of having [laughter] a medically complex child. Versus now, where we're the counselor, we're the parent, we're the enforcer, we're the rule maker, and we're also the teachers when it comes to education. Yes, the teachers are phenomenal, and they've done everything to be understanding of what is going on. But, in the end of the day, we're the ones like, go to school, go to class, you can't be tardy for a online school. . .So, I feel like there's a lot more roles we have taken that we did not take, or have to take before, or even have to think about it, so. -ParentNonOnc
		So, prior to COVID everybody came into our house because he didn't go to schools, but it was a bit of adjustment. The first two or three weeks [my child] did not want to work for me because. . .I've never made him work like that. I was always behind the scenes or like I would help with therapists or school or something . . . but I was never the one saying, you need to do this...Because pre-COVID I always felt like I wanted to be mom and like not being the one that's saying, you need to do this, so I let other people tell him what he had to do and I just was the snuggle buddy. So, it was a bit of adjustment, but he does really good now. We've come a long ways. -ParentNonOnc
	Delay in care (n = 8)	Not really. The biggest thing was back in May or April I should say, right before she had her surgery, because it was unclear – we were supposed to have the surgery in March but because of COVID it was pushed off, pushed off. And it got to the point where the surgery became urgent. -ParentNonOnc
		She's had a lot of, I don't know, dysreflexia episodes where her blood pressure goes up and she . . . had an MRI in the beginning of Oct – no, the end of September. So that was good. . .but it just seems like it took a long time to – it just took longer than normal, I think, to get the ball rolling on things and just to really get the point across of how – her decline, I guess. Between all the different disciplines that deal with her. -ParentNonOnc
	Changes in travel to medical facility (n = 6)	At first it was horrible, honestly. It was so nerve racking because we also we don't have a car here so we Uber. So that was another of my issues – like should we get some – like I don't even know – can you come pick me up in an ambulance or something I don't know. But then it just it got better.-ParentOnc
		It was a very different experience because, as we were driving, every state was closing and there was so much like, oh, unknown. We were passing New York, and they said, oh, my god, they're gonna catch you because your license plate says North Carolina, or what have you, and you cannot stay, you cannot do this, and you cannot do that. It was a lot of unknown and a lot of speculation, but we made it to Boston and we stayed there for, I believe, three – four weeks total-ParentNonOnc

(*Continued*)

Table 2
Continued

Theme	Code	Descriptive Quote
Telehealth	Ease or efficiency of telehealth (n = 27)	I'd say the biggest change is all the virtual, all the virtual appointments. Which, honestly, if she's doing well, I love. I don't mind not having to drive all the way into town for visits where it's really not required for them – for her to be seen. -ParentOnc
		I think now that we have done this virtual thing, I think pandemic or no pandemic, before we race off to Boston we would ask for a virtual visit. Because now that I have this option, like I feel like we're four and a half hours from Boston. If we can do a virtual visit and have anything accomplished, let's do it. . .his primary care locally we even do virtual visits with. It's so much easier with him. -ParentNonOnc
	Limitations of telehealth (n = 18)	But some visits, I do find, are harder. If it's a pulmonary, or certain appointments, as long as they see him and we're updating them, it's okay. But his orthopaedic doctor likes to check muscle tone, or things like that you easily put your hands on him to feel. So, appointments like that are more difficult. But your basic appointment like a check in, are easier, so. -ParentNonOnc
		I'd prefer to have it in person, to seen by a doctor because, that way, you're telling them what's going on, what's the problem. And they can figure out like, okay, let's get you some blood tests, let's do an ultrasound, let's do an x-ray, see what's going on. That's what I prefer. -AYANonOnc
	Technical challenges with telehealth (n = 24)	The only one thing with all these Zoom calls is you make an appointment – two months prior, you can't find your Zoom call. The only thing I would suggest is you do reminders that – the day before. . .because maybe some people organized things correctly. -ParentNonOnc
		I just think it's sort of small glitches in the technology with the little bits of lag that we have now and the cutting out and all this kinda stuff. It just makes it difficult to kind of connect on this – on the same level. So, I could see it being more difficult meeting a new provider. -ParentOnc
	Application to future care (n = 21)	I really feel like if it's certain doctors, I will go in. Certain rechecks – there is just – there are literally five-minute rechecks. I think that they may be able to attend to more patients if those rechecks are done like a Zoom day. Like Monday, he's only on Zoom and they're just the rechecks of – there are some appointments that I don't necessarily need to spend or take someone like [my child is] in a wheelchair. -ParentNonOnc
Challenges Faced	Availability of supplies (n = 7)	I can't get gloves, I can't get gloves anywhere, I can't get syringes. I can't get all these basic things that I used to buy all the time. We're supposed to be changing [my child's] diapers with gloves on because she's on chemo. That's not happening. Because all these people are hoarding gloves because they can't touch things. -ParentNonOnc
Parental Mental Health	Negative impact on health (n = 16)	So, it was good in some aspects, bad in others. I'd want to say more on a personal level it was bad because it made the whole process like really, really lonely for me, especially going into the hospitals because when I was there no one could come with me to any of her appointments. . .no one could come visit when we were in the hospital and during each cycle we were in the hospital for almost five days straight and no one could come. . . So, it was very isolating for me in a lot of ways. -ParentOnc
	Safety (n = 13)	Oh, I would say like just the general feeling – like not feeling safe. I don't feel safe in general in most places. And not feeling safe around the people we love the most and not being able to – so like not being able to see Grandma or – making the decision to see Grandma and then stressing about it for the next five days. -ParentNonOnc
	Strategies families use (n = 12)	Well, I think the biggest strategy was just trying to be outside as much as possible, like go on hikes and, for example, one of my daughters– but she is now 15 and

Benefits and Challenges to Telehealth

Almost all families (n = 27) had at least one telehealth videoconference visit during this time. Benefits of telehealth included ease and efficiency in appointments and less travel and wait time, resulting in more time for their children's care. However, more than half of the families (n = 23) reported having some technical problems. Difficulties included audiovisual malfunction, unstable WIFI, trouble navigating electronic systems and locating the link to the videoconference visit if it was sent a long time before the encounter or if their child had many appointments. About half of the parents (n = 15) expressed a preference for continuing to have a hybrid model for care in which patients have the option to choose telehealth appointments and in-person services when necessary. Most parents shared that their preference for telehealth versus in-person visits would vary based on the type of specialty, the nature of the visit (routine follow-up vs. initial consultation) and the clinical status of their child. Only eight parents stated a strong preference for in-person visits.

Impact on Parents

In addition to challenges regarding caring for their child, parents also reflected on a negative impact on their mental health (n = 14). Parents described feeling more isolated during their child's care due to the inability to share the work with another caregiver when in medical facilities (n = 7) and feeling drained from taking on more roles in their child's care (n = 8). Parents also shared difficulties in dealing with personal feelings of safety and uncertainty (n = 11). Strategies parents used to address these challenges included adjusting schedules to work remotely, taking time off from work, and finding time for outdoor leisure activities.

Discussion

This study provides the first in-depth look into the experience of families of seriously ill children during COVID-19. Specifically, we found that families are facing considerable challenges related to caring for their children at home. Whereas they typically rely on a host of in-home services and staff and community support,[17,33–35] families are now providing care in isolation.[2] Parents also reported isolation as a big problem when at health care facilities due to the limitation in number of family members per patient permitted.[5] As a result of these challenges, parents describe substantial feelings of distress. On a positive note, many parents have adapted to virtual modalities of care during the pandemic which are preferred in certain instances, even when some limitations are recognized.[23]

Most families experienced a substantial shift in the way they were able to care for their child due to COVID-19. These changes were not only determined by the type of therapy and whether it could safely occur at home or virtually but they were also influenced by the child's primary diagnosis.[22] For example, children receiving cancer directed treatment continued their treatment during the COVID-19 pandemic fairly uninterrupted. In comparison, the majority of children receiving in-home or school-based services such as physical, speech, and occupational therapies had these services cancelled or shifted to telehealth.[36–40]

Multiple factors may have contributed to this discrepancy. Many families and clinicians seem to be weighing the risk versus benefit of in-person services. It is probable that for clinicians and parents of children with cancer, the main driver was to continue potentially curative anti-cancer therapy at the expense of increased risk of COVID. Among parents of children with non-oncologic chronic conditions, minimizing COVID exposure may have prevailed over therapies that in general are provided to improve quality of life and overall wellbeing and to decrease suffering.[41–45] The health system may have enhanced this discrepancy by prioritizing the continuation of certain services over others. However, the long-term, unintended consequences of foregoing routine therapies for a significant period in children with non-oncologic serious illnesses may have been overlooked. Further research is warranted to assess the impact of care changes or suspension of therapies with regard to, for example, child mobility, behavior, cognitive function, respiratory status and potentially longevity.

The overall satisfaction with telehealth virtual care reported in this study is consistent with other studies that have assessed satisfaction with telehealth within the general or specialty-specific pediatric populations for discussion based visits.[46–50] In a retrospective survey among two-hundred children who had telehealth visits for otolaryngology in the United Kingdom during COVID-19, the overwhelming majority reported a positive experience with their virtual consultation.[46] Parents in our study shared a desire to have an option for a "Zoom" day for all of their providers so they could complete all visits (mostly discussion-based visits) through telehealth and limit the number of in-person visits to minimize travel burden and exhaustion for both the parent and child. One important distinction our study highlights are the limitations of telehealth. For example, parents noted that for certain types of specialty visits and depending on the clinical status of their child, in-person visits may be preferable to ensure access to physical examination or hospital-based services. This finding is consistent with a study by Murphy et al that found low satisfaction with telehealth for therapy-based service among 276 children with disabilities.[36] Murphy et al also found that satisfaction with telehealth services was associated with access to adequate virtual visit technology and type of service provided (i.e., physical therapy versus early intervention). These studies suggest providers should work with families[51] to ensure adequate technology is available and to integrate teaching support for families to properly assist with therapy to enhance telehealth services.

Finally, this study highlights the heightened role parents have in maintaining their child's care during COVID-19 and how it affects their own wellbeing. Studies this year have shown parents are facing high levels of stress as a result of more responsibilities with their children at home.[52–55] While not designed to compare across populations, our study suggests that parents of seriously ill children may bear an even greater emotional burden. Parents who became the sole companion for their child in a medical facility experienced more feelings of isolation and burnout compared to before the pandemic. The impact of increased responsibilities on parental mental health shows the value in supporting these parents.[56,57] Delineating how best to do so should be a research priority.

Our study has several limitations. The first is the majority of participants in this study were mothers.

Given only three fathers participated, we cannot fully describe their perspective. While the reflection period occurred later in 2020, recall bias is possible and family experiences may have varied throughout the pandemic. We were unable to include families who did not speak, read or write English. Thus, we cannot generalize the findings to non-English speaking families. We also recognize all individuals in this study had access to a smartphone, tablet or laptop in order to complete the study. Due to the COVID-19 pandemic, recruitment was limited to virtual methods therefore we were unable to reach families without access to technology. Further, we employed only a single interviewer which may have resulted in less neutrality in later interviews once multiple themes had been discovered in early analyses. Additionally, we are unable to describe the AYA experience since only three participated, in part related to the nature of the underlying illnesses. This finding suggests a greater need to include AYA in research to highlight their specific experiences. Despite these limitations, this study also has many strengths. Notably, our interviewer was not a member of the clinical team and thus participants may have more freely shared their experiences with care. Although we were unable to quantify the negative impact on parental mental health, it is important to note that these findings were self-reported in almost half of parents. Our participation rate, while under fifty percent, is robust given the ongoing nature of the pandemic. While the intensity of family challenges is likely to vary based on sociodemographic factors, our findings provide a snapshot of the universally shared experience during COVID-19.

Conclusion

This study uncovered multiple ways in which COVID-19 impacted families caring for children with serious illnesses. We found that the pandemic increased family burden and parent distress in caring for their children. Future research should focus on long-term effects on child and family wellbeing. The pandemic also highlighted the benefits and challenges to telehealth. As clinicians and families begin to move forward and learn from experiences during COVID-19, it is apparent that the inclusion of a hybrid model, one in which patients have the option to choose telehealth or in-person, when necessary, has the potential to improve access to and satisfaction with care.

Author Contributions

Ms. Beight conceptualized and designed the study, designed data collection instruments, collected data, completed initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript. Ms. Helton conceptualized and designed the study, completed initial analyses and reviewed and revised the manuscript. Mrs. Avery conceptualized and designed the study, assisted with data collection instruments, and reviewed and revised the manuscript. Drs. Wolfe and Dussel conceptualized and designed the study, coordinated and supervised data collection, and critically reviewed the manuscript for important intellectual content. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jpainsymman.2021.07.017.

References

1. Ekberg K, Weinglass L, Ekberg S, Danby S, Herbert A. The pervasive relevance of COVID-19 within routine paediatric palliative care consultations during the pandemic: a conversation analytic study. Palliat Med 2020;34:1202–1219. https://doi.org/10.1177/0269216320950089.

2. Jonas DF, Drouin K, Greenman J, et al. The long shadow: collateral impact and finding resilience amidst a global pandemic pediatric palliative care social work during COVID-19. J Soc Work End-of-Life Palliat Care 2021: 1–19. https://doi.org/10.1080/15524256.2021.1894312. Published online March 15.

3. Kalluri N, Kelly C, Garg A. Child care during the COVID-19 pandemic: a bad situation made worse. Pediatrics 2021;147:e2020041525. https://doi.org/10.1542/peds.2020-041525.

4. Karpman M, Gonzalez D, Kenney G. Parents are struggling to provide for their families during the pandemic . Urban Institute at Robert Wood Johnson Foundation; 2020. p. 1–15 https://www.urban.org/sites/default/files/publication/102254/parents-are-struggling-to-provide-for-their-families-during-the-pandemic_2.pdf.

5. Diskin C, Orkin J, Agarwal T, Parmar A, Friedman JN. The secondary consequences of the COVID-19 pandemic in Hospital Pediatrics. Hosp Pediatr 2021;11:208–212. https://doi.org/10.1542/hpeds.2020-002477.

6. Chanchlani N, Buchanan F, Gill PJ. Addressing the indirect effects of COVID-19 on the health of children and young people. CMAJ 2020;192:E921–E927. https://doi.org/10.1503/cmaj.201008.

7. Cost KT, Crosbie J, Anagnostou E, et al. Mostly worse, occasionally better: impact of COVID-19 pandemic on the mental health of Canadian children and adolescents. Eur Child Adolesc Psychiatry 2021. https://doi.org/10.1007/s00787-021-01744-3. Published online February 26.

8. Ferrara P, Franceschini G, Corsello G, et al. Children witnessing domestic and family violence: a widespread occurrence during the coronavirus disease 2019 (COVID-19) pandemic. J Pediatr 2021:S0022347621004236. https://doi.org/10.1016/j.jpeds.2021.04.071. Published online May.

9. Kawaoka N, Ohashi K, Fukuhara S, et al. Impact of school closures due to COVID-19 on children with neurodevelopmental disorders in Japan. J Autism Dev Disord 2021. https://doi.org/10.1007/s10803-021-05119-0. Published online June 3.

10. Cardenas MC, Bustos SS, Chakraborty R. A 'parallel pandemic': the psychosocial burden of COVID-19 in children and adolescents. Acta Paediatr 2020;109:2187–2188. https://doi.org/10.1111/apa.15536.

11. Gupta S, Jawanda MK. The impacts of COVID-19 on children. Acta Paediatr 2020;109:2181–2183. https://doi.org/10.1111/apa.15484.

12. Ferrara P, Franceschini G, Corsello G, et al. The dark side of the web—a risk for children and adolescents challenged by isolation during the COVID-19 pandemic. J Pediatr 2020:S0022347620312701. https://doi.org/10.1016/j.jpeds.2020.10.008. Published online October.

13. Singh S, Roy D, Sinha K, et al. Impact of COVID-19 and lockdown on mental health of children and adolescents: a narrative review with recommendations. Psychiatry Res 2020;293:113429. https://doi.org/10.1016/j.psychres.2020.113429.

14. Lazzarin P, Avagnina I, Divisic A, et al. Management strategies adopted by a paediatric palliative care network in northern Italy during the COVID-19 pandemic. Acta Paediatr 2020;109:1897–1898. https://doi.org/10.1111/apa.15411.

15. Kaspers GJL. COVID-19: how will this impact children with cancer, now and in the future? Expert Rev Anticancer Ther 2020;20:527–529. https://doi.org/10.1080/14737140.2020.1781621.

16. Gassman-Pines A, Ananat EO, Fitz-Henley J. COVID-19 and parent-child psychological well-being. Pediatrics 2020;146:e2020007294. https://doi.org/10.1542/peds.2020-007294.

17. Feudtner C, Kang T, Hexem K, et al. Pediatric palliative care patients: a prospective multicenter cohort study. Pediatrics 2011;127:1094–1101. https://doi.org/10.1542/peds.2010-3225.

18. Saini AG, Suthar R. COVID-19 pandemic: the concerns of pediatric neurologists. Ann Indian Acad Neurol 2020;23:358–359. https://doi.org/10.4103/aian.AIAN_407_20.

19. Bhavsar SM, Clouser KN, Gadhavi J, et al. COVID-19 in pediatrics: characteristics of hospitalized children in New Jersey. Hosp Pediatr 2021;11:79–87. https://doi.org/10.1542/hpeds.2020-001719.

20. Horsky J, Morgan SJ, Ramelson HZ. Coordination of care for complex pediatric patients: perspectives from providers and parents. AMIA Annu Symp Proc 2014;2014:681–690.

21. Ogimi C, Englund JA, Bradford MC, et al. Characteristics and outcomes of coronavirus infection in children: the role of viral factors and an immunocompromised state. J Pediatr Infect Dis Soc 2019;8:21–28. https://doi.org/10.1093/jpids/pix093.

22. Aishworiya R, Kang YQ. Including children with developmental disabilities in the equation during this COVID-19 pandemic. J Autism Dev Disord 2020. https://doi.org/10.1007/s10803-020-04670-6. Published online August 20.

23. Nicholas DB, Belletrutti M, Dimitropoulos G, et al. Perceived impacts of the COVID-19 pandemic on pediatric care in Canada: a roundtable discussion. Global Pediatric Health 2020;7. https://doi.org/10.1177/2333794X20957652. 2333794X2095765.

24. Dhiman S, Sahu PK, Reed WR, et al. Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. Res Dev Disabil 2020;107:103790. https://doi.org/10.1016/j.ridd.2020.103790.

25. COVID-19 interactive data dashboard. Mass.gov. Published June 30, 2021. Available from https://www.mass.gov/info-details/covid-19-response-reporting#covid-19-weekly-public-health-report-

26. New COVID-19 Cases Worldwide. Johns Hopkins Coronavirus Resource Center. Available from https://coronavirus.jhu.edu/data/new-cases

27. U.S. COVID-19 vaccine tracker. Mayo Clinic. Accessed July 7, 2021. Available from https://www.mayoclinic.org/coronavirus-covid-19/vaccine-tracker

28. Harris P, Taylor R, Thielke R, et al. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009;42:377–381.

29. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software platform partners. J Biomed Inform 2019;95:103208. https://doi.org/10.1016/j.jbi.2019.103208.

30. Mertens D, Wilson A. Program evaluation theory and practice: a comprehensive guide. 12th New York, NY: Gilford Press; 2012.

31. Moser A, Korstjens I. Series: practical guidance to qualitative research. Part 3: sampling, data collection and analysis. Eur J Gen Pract 2021;24:9–18. https://doi.org/10.1080/13814788.2017.1375091.

32. U.S. Census Bureau. United States Zip Codes. Available from https://www.unitedstateszipcodes.org/

33. Siden H. Pediatric palliative care for children with progressive non-malignant diseases. Children 2018;5:28. https://doi.org/10.3390/children5020028.

34. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics 2011;127:529–538. https://doi.org/10.1542/peds.2010-0910.

35. Elias ER, Murphy NA. the COUNCIL ON CHILDREN WITH DISABILITIES. Home care of children and youth with complex health care needs and technology dependencies. Pediatrics 2012;129:996–1005. https://doi.org/10.1542/peds.2012-0606.

36. Murphy A, Pinkerton LM, Bruckner E, Risser HJ. The impact of the novel coronavirus disease 2019 on therapy service delivery for children with disabilities. J Pediatr 2020:S0022347620315705. https://doi.org/10.1016/j.jpeds.2020.12.060. Published online December.

37. Cacioppo M, Bouvier S, Bailly R, et al. Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: the ECHO French

survey. Ann Phys Rehabil Med 2020:101429. https://doi.org/10.1016/j.rehab.2020.08.001. Published online August.

38. Jeste S, Hyde C, Distefano C, et al. Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. J Intellect Disabil Res 2020;64:825–833. https://doi.org/10.1111/jir.12776.

39. Houtrow A, Harris D, Molinero A, Levin-Decanini T, Robichaud C. Children with disabilities in the United States and the COVID-19 pandemic McLaughlin M, Vercler C, eds PRM 2020;13:415–424. https://doi.org/10.3233/PRM-200769.

40. Maltais DB, Wiart L, Fowler E, Verschuren O, Damiano DL. Health-related physical fitness for children with cerebral palsy. J Child Neurol 2014;29:1091–1100. https://doi.org/10.1177/0883073814533152.

41. Mack JW, Joffe S, Hilden JM, et al. Parents' views of cancer-directed therapy for children with no realistic chance for cure. JCO 2008;26:4759–4764. https://doi.org/10.1200/JCO.2007.15.6059.

42. Bluebond-Langner M, Belasco JB, Goldman A, Belasco C. Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. JCO 2007;25:2414–2419. https://doi.org/10.1200/JCO.2006.08.7759.

43. Hill DL, Miller V, Walter JK, et al. Regoaling: a conceptual model of how parents of children with serious illness change medical care goals. BMC Palliat Care 2014;13:9. https://doi.org/10.1186/1472-684X-13-9.

44. Granek L, Barrera M, Shaheed J, et al. Trajectory of parental hope when a child has difficult-to-treat cancer: a prospective qualitative study: parental hope when a child has difficult-to-treat cancer. Psycho-Oncology 2013;22:2436–2444. https://doi.org/10.1002/pon.3305.

45. Lee KJ, Hill DL, Feudtner C. Decision-making for children with medical complexity: the role of the primary care pediatrician. Pediatr Ann 2020;49:e473–e477. https://doi.org/10.3928/19382359-20201013-01.

46. Darr A, Senior A, Argyriou K, et al. The impact of the coronavirus (COVID-19) pandemic on elective paediatric otolaryngology outpatient services – an analysis of virtual outpatient clinics in a tertiary referral centre using the modified paediatric otolaryngology telemedicine satisfaction survey (POTSS). Int J Pediatr Otorhinolaryngol 2020;138:110383. https://doi.org/10.1016/j.ijporl.2020.110383.

47. Chuo J, Macy ML, Lorch SA. Strategies for evaluating telehealth. Pediatrics 2020;146:e20201781. https://doi.org/10.1542/peds.2020-1781.

48. McNeil MJ, Kaye EC, Vedaraju Y, et al. Global experiences of pediatric palliative care teams during the first 6 months of the SARS-CoV-2 pandemic. J Pain Symptom Manage 2021:S0885392421002712. https://doi.org/10.1016/j.jpainsymman.2021.03.016. Published online March.

49. Ingersoll B, Berger NI. Parent engagement with a telehealth-based parent-mediated intervention program for children with autism spectrum disorders: predictors of program use and parent outcomes. J Med Internet Res 2015;17:e227. https://doi.org/10.2196/jmir.4913.

50. Semprino M, Fasulo L, Fortini S, et al. Telemedicine, drug-resistant epilepsy, and ketogenic dietary therapies: a patient survey of a pediatric remote-care program during the COVID-19 pandemic. Epilepsy Behav 2020;112:107493. https://doi.org/10.1016/j.yebeh.2020.107493.

51. Rao PT. A paradigm shift in the delivery of physical therapy services for children with disabilities in the time of the COVID-19 pandemic. Phys Ther 2021;101:pzaa192. https://doi.org/10.1093/ptj/pzaa192.

52. Willner P, Rose J, Stenfert Kroese B, et al. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. J Appl Res Intellect Disabil 2020;33:1523–1533. https://doi.org/10.1111/jar.12811.

53. Tso WWY, Wong RS, Tung KTS, et al. Vulnerability and resilience in children during the COVID-19 pandemic. Eur Child Adolesc Psychiatry 2020. https://doi.org/10.1007/s00787-020-01680-8. Published online November 17.

54. Janssen LHC, Kullberg M-LJ, Verkuil B, et al. Does the COVID-19 pandemic impact parents' and adolescents' well-being? An EMA-study on daily affect and parenting Cimino S, ed. PLoS One 2020;15:e0240962. https://doi.org/10.1371/journal.pone.0240962.

55. Patrick SW, Henkhaus LE, Zickafoose JS, et al. Well-being of parents and children during the COVID-19 pandemic: a national survey. Pediatrics 2020;146:e2020016824. https://doi.org/10.1542/peds.2020-016824.

56. Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? J Autism Dev Disord 2020. https://doi.org/10.1007/s10803-020-04577-2. Published online July 31.

57. Darlington AE, Morgan JE, Wagland R, et al. COVID-19 and children with cancer: parents' experiences, anxieties and support needs. Pediatr Blood Cancer 2021;68. https://doi.org/10.1002/pbc.28790.