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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.

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. Families have faced increased material hardships including housing and food insecurities and access to safe child care as a result of COVID-19.
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.18,19,15 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 vulnerabilities21 and maintaining routine care such as disease directed therapies, school-based therapies, and home nursing for activities of daily living support.5,14,15,22 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.

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

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

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.
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. 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.

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).

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 1

| Participant Demographics and Clinical Characteristics | Child N = 29 | Parents N = 29 |
|------------------------------------------------------|-------------|----------------|
| No. (%)                                              | 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 enrollment in PPC study = yes                  |             |
| 15 (52)                                              |             |
Table 2
Descriptive Quotes

| Theme                              | Code       | Description                                                                 |
|------------------------------------|------------|-----------------------------------------------------------------------------|
| 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. —ParentNonOncb |
| 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 them, they’re just with him the whole time. —ParentOne |
| Change in type of clinical encounter (n = 20) | 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. —ParentOne |
| Parents taking on additional roles (n = 10) | 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. —ParentOne |
| Delay in care (n = 8) | 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 |
| Changes in travel to medical facility (n = 6) | 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 |

(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. -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 |
| Technical challenges with telehealth    | Application to future care (n = 24) | The only one thing with all these Zoom calls is you make an appointment, and then they send it. Well, if you make your 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 |
| 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. -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. -ParentNonOnc |
| 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 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. |

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...
**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. \( 25 \) 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. \( 11−45 \)

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. \( 16−50 \) 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 \( 41 \) 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, 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.

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