Health Care Providers’ Perspectives on COVID-19 and Medical Neglect in Children with Life-Threatening Complex Chronic Conditions

Ross W. Cleveland1,2 · Rachel S. Deming1,2 · Gabriel Helton1 · Celeste R. Wilson2,3 · Christina K. Ullrich1,2,4

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Abstract

Purpose Little is known regarding medical neglect in children with Life-Threatening Complex Chronic Conditions (LT-CCCs). We examined the impact of COVID-19 on concern for medical neglect in this population.

Methods Qualitative interview study of multi-disciplinary health care providers (HCPs) from critical care, palliative care, and complex care services on the topic of medical neglect in children with LT-CCCs. We used inductive thematic analysis to generate themes. Findings presented herein are derived from a sub-analysis of the larger study that focused specifically on discussion of COVID-19 by HCPs.

Results 9 of the 20 HCPs interviewed mentioned COVID-19 as influencing situations of potential medical neglect. These 9 represent all disciplines and teams. Interviewees reported COVID-19 increased burden on parents and likelihood of medical neglect due to: 1) Familial distancing from medical and social support and, 2) Changes to medical care delivery that impaired the medical community’s ability to engage and support families.

Conclusions The COVID-19 pandemic has exposed the fragility of the medical and social systems that supports families of children with LT-CCCs. These findings are consistent with previous literature that suggest that the COVID-19 pandemic has increased the risk for child maltreatment. It additionally highlights the vulnerability of this patient population.

Keywords Medical Complexity · Complex Chronic Conditions · Medical Neglect

Introduction

Medical neglect is a rare, but deadly form of child maltreatment. Despite making up merely 2% of reports to child protective services annually, medical neglect accounts for nearly 10% of maltreatment-related deaths (U. S. Department of Health and Human Services, 2017). Despite the lethality of this type of maltreatment, it is relatively understudied compared to other forms of abuse and neglect.

Medical neglect is likely to be first recognized by medical personnel, be it by missed appointments, admission for preventable illness, or medication misuse. In 2007, the American Academy of Pediatrics published five criteria for the diagnosis of medical neglect to be made: 1) a child is harmed or is at risk of harm because of lack of health care, 2) the recommended health care offers significant net benefit to the child, 3) the anticipated benefit of the treatment is significantly greater than its morbidity, so that a reasonable caregiver would choose treatment over nontreatment, 4) it can be demonstrated that access to health care is available and not used, 5) the caregiver understands the medical advice given (Jenny et al., 2007). More recently, Boos and Fortin argued that, from a clinician’s perspective, the only requirements for medical neglect to be present are that there is a treatment available, it would offer significant benefit, and the benefit is greater than the burden (Boos & Fortin, 2014). Despite such criteria, there is substantial variation in how medical personnel report concerns for medical neglect (Johnson, 1993).
Methods
Study Design and Population
This analysis was conducted as part of a study designed to generate understanding of how the medical community conceptualizes and approaches concerns for medical neglect. It focused on children with LT-CCCs in a large tertiary medical center. Within each team (Pediatric Palliative Care (PPC), Intensive Care (ICU), Complex Care (CCS)), recruitment began with professional outreach via email and Zoom meeting from the research team to contacts on the teams of interest and then expanded through further introductions and outreach until thematic saturation was achieved. All recruitment for interviews was performed via institutional email. Potential subjects were sent an initial recruitment email outlining the purpose of the study and explaining what would be involved in participation. Two subsequent recruitment emails were sent at two and four weeks following initial email. Potential subjects could opt-out at any time. If there was no response following third email, potential subjects were considered to have opted out. Participation was confidential and known only to study personal. This study was approved by the Boston Children’s Hospital Institutional Review Board.

Data Collection
Semi-structured, in-depth interviews were conducted from October 2020 through February 2021. A semi-structured interview guide was used to facilitate each interview. This guide was iteratively updated and refined based on review of the transcripts. The interview guide did not include items related to the COVID-19 pandemic. All interviews were performed by single author (RWC) were one-on-one, in English, and conducted electronically via Zoom or via telephone. All were digitally audio recorded and transcribed verbatim, removing any personal identifiers. All transcripts and audio recorded interviews were stored on a password-protected institutional network drive. No identifying patient information was discussed during interviews. Interviews lasted 33–55 min. Interviewees received a small token of appreciation ($25 gift card) for participation. Participant demographics including age, gender, race/ethnicity, role on team, primary working unit, and years of experience working with children with LT-CCCs were obtained prior to interview. Participants were free to request that their interview transcript not be included in analysis.

Data Analysis
Our stated goal in this project of generating understanding of how clinicians approach concerns of medical neglect in
Results

In total, 30 health care providers (HCPs) were invited to participate in this study. 20 agreed to participate, were enrolled, and had interviews completed. Of these 20 HCP interviewees, nine of them discussed the effect of COVID-19 in relation to concerns for medical neglect in children with LT-CCCs. These nine participants represent all disciplines (nurse, social worker, nurse practitioner, physician) as well as all medical teams (ICU, CCS, PPC) included in the study. They also represent a wide range of ages and years in practice. Demographics are presented in Table 1.

According to HCPs, the effect that COVID-19 has had on concerns for medical neglect were multiple and varied. They contributed to an increase in familial isolation and in parental burden of care contributing to an increased likelihood of and concern for medical neglect in children with LT-CCCs. This was discussed in two ways: First, families distanced from typical supports either intentionally or because of COVID-19 restrictions; and second, the medical system was less able to reach out and support families due to changes in medical care delivery.

Theme 1: COVID-19 led to familial distancing from support systems.

Many interviewees discussed that for children with LT-CCCs, school often represents an important support. In addition to offering vital child social interaction, it provides an opportunity for respite for families understandingly struggling with the intense medical needs of their child. The combination of fear of infection and restriction of in-person schooling led to many parents keeping their children at home full time. Without any respite, there was concern that the quality of the medical care provided at home suffered. As one nurse stated:

…families that can't send their kids to school right now that have medical needs. You know, these families are, they're tired and they're afraid to take them anywhere. They're afraid of COVID so it's, you know, 24/7 just themselves? Can that lead to maybe some care that's not optimal? Probably for some families. (HCP05)

Similarly, another provider remarked that the legal obligation to send your child to school can often act as a safety net. School provides another set of eyes to evaluate for possible

| Health Care Provider Characteristic | Discussed Covid-19 (n = 9) | Total (n = 20) |
|------------------------------------|---------------------------|---------------|
| Gender Female                       | 9 (100)                   | 17 (85)       |
| Race/Ethnicity White/Non-Hispanic   | 9 (100)                   | 17 (85)       |
| Age Median (Range) 45 (25–67)       | 43.5 (25–67)              |               |
| Role Nurse                         | 2 (22)                    | 4 (20)        |
| Social Worker                      | 4 (44)                    | 5 (25)        |
| Physician                          | 2 (22)                    | 10 (50)       |
| Nurse Practitioner                 | 1 (11)                    | 1 (5)         |
| Age Median (Range) 12 (2.5–31)      | 12.5 (1–31)               |               |
| Years of Experience                |                           |               |

CCS Complex Care Service, ICU Intensive Care Unit, PPC Pediatric Palliative Care

Table 1 Demographics of all study participants and those who discussed Covid-19 during interview

...
neglect. Without this, she worried about the increased chance of unrecognized medical neglect.

And I have to tell you, I mean, I’m not lying when I say just I felt kind of a pit in my stomach with COVID amongst the many reasons. There is a reason, safety reason for families that have difficulty maintaining a real routine for their children to hide behind and escape what has been a safety net for our kids to school. (HCP09)

In addition to issues related to school, providers also commented on the impact that COVID-19 has had on home health care. Just as parents are fearful of sending their medically fragile children to school, they are reticent to allow nurses into the home due to infectious concerns. This eliminates yet another source of medical and social support as well as removing a medically trained observer who might be able to identify unsafe situations. As one provider put it:

So that’s a huge factor huge, huge I mean, COVID now has put a lot of other families in the situation that they’re not accepting help at home because of the fear of infections. And I’ve had family, especially during the lockdown, that were falling apart emotionally because they had not done this kind of like 24/7 job in a while and they were back doing that. That was difficult. (HCP16)

One provider summarized these factors as all contributing to situations where families who were previously caring for their children through a network of supports were now dealing with a complex child alone:

…and especially now with COVID where these kids are not going to school. Nursing is not going into the homes. The family is really on their own. They’re not going to appointments. It’s very isolating. I can see, you know, things may be difficult for these families and maybe things will happen that they think are happening, but they’re used to having a bunch of other people help with the care of these kids. (HCP05)

Theme 2: COVID-19-related changes to medical care delivery have affected the medical community’s ability to effectively engage with and support families.

In addition to having an impact on how families have become more isolated from typical supports, as outlined above, many providers also commented on how COVID-19-related changes to health care delivery have contributed to the medical system becoming less able to support families, thereby increasing familial isolation and subsequent concerns for medical neglect. Families with children with LT-CCCs are often well-connected to their medical providers given the frequency of appointments and medical exacerbations. The COVID-19 pandemic brought significant changes to the standard medical care. Most non-urgent medical appointments were canceled or postponed, and many staff were transitioned to remote work. This contributed to further isolation and hardships for families of children with LT-CCCs.

One provider remarked on how the timing of this study was particularly interesting, given the effect that COVID-19 has had:

I also think that it just you’re doing this [study] at an incredibly difficult time and maybe that’s the that’s part of your plan. But I think like this this whole COVID complexity probably does not support any families that are kind of on the brink of not being able to complete appointments. (HCP17)

COVID-19 has also contributed to the negotiations that go on between parents and providers concerning onerous appointments and procedures. Some parents are resistant to medical care they view as unnecessary. This hesitancy to engage in medically appropriate care can have significant effects on children with LT-CCCs and can be viewed as medically neglectful. Convincing reluctant parents to bring a medically delicate child in for medical care is even more difficult when there is a safety concern in even leaving the house. During one conversation regarding international patients, one provider remarked: “And parents…have been reluctant to bring her in for testing. And some of it is wrapped up in COVID and the other things but we’ve had a lot of conversations about like what can we do from afar?” (HCP13).

Even for parents who are desirous of interventions and assistance from the medical community, COVID-19 has impacted their ability to connect. One provider described a mother who had openly discussed her resource limitations and psychiatric needs, and how this provider struggled to put supports in place due to restrictions and changes wrought by COVID-19:

I think we did a lot of work in trying and of course, this is also in COVID time. So resources that might have been available to this mom were not. So we’ve made a lot of referrals to housing advocates, and she had gotten way behind in her rent. She was home schooling her seven kids and had to leave her work. So she was financially devastated. So we applied for some catastrophic illness funds. And we also worked hard to make sure that her providers that she was able to access her providers at Brigham and Women’s, her psychiatrist who was there, she was also cared for by a psychologist. But like with COVID trying to reach a psychiatrist with all the administrative people are working remotely. It’s very hard for her to do, even though she’s quite a good advocate for herself. (HCP07)
Similarly, another provider outlined how COVID-19 has added to the difficulty in properly educating and training parents on the complex medical care that their children require. This in turn leads to concerns that the parents will not be successful in providing the medical care needed for the child upon discharge.

We recently had a case where a parent was unable to be here at the hospital for teaching new medications, with COVID, with the visitors restrictions, again, a single parent was unable to come to the hospital for teaching at a regular daytime time. – HCP02

One substantial change that COVID-19 has brought about is the increase in telehealth. Providers commented on this change and described both the advantages and disadvantages of telehealth in this population. One provider pointed out that while telehealth had largely taken the place of in-person appointments, for children with LT-CCCs there is something missed when they are not assessed in person:

... in this particular case, I think COVID had a huge impact on it. And this patient who is scheduled for follow up then sort of got lost to one service and then everything else converted to telehealth for another service. And I think while telehealth is great, it also has challenges and may not be able to actually assess what’s going on in a home. (HCP12)

At the same time, another provider pointed out that the broader implementation of telehealth may be substantially important for these children and families. Although it does not replace the in-person visit, it can allow providers to check in with families more easily. For children who are difficult to transport, this could serve as a helpful first step when a problem arises at home:

I would love to have more people involved in...like some type of like home system programs where, you know, families who may not have reliable transportation or like it's really hard to take a trach vented kid anywhere or even a kid on oxygen. Like, that's hard. I can't even imagine, and so just kind of being able to offer more in-home services. I do wonder, like with the kind of expansion of telehealth through COVID if that will be helpful for kids and families to be able to have more like options to be at home [and] get information, obviously, you can’t do everything over telehealth, but if that could help prevent some of these kids from coming in super sick, if the parents are able to like speak with their providers in a more formal way. (HCP14)

Discussion

Our results demonstrate that HCPs are cognizant of the effect COVID-19 has had on the families of children with LT-CCCs. Nearly half of all participants spontaneously mentioned it up as an important factor. The COVID-19 pandemic and the societal changes it has brought about have been felt in almost all domains. Therefore, it is perhaps not surprising that it was discussed frequently in these interviews. However, by examining how COVID-19 was discussed, we can see important lessons in care for children with LT-CCCs.

Our findings indicate that care for children with LT-CCCs is perceived to be difficult, costly, and straining for parents. The loss of any kind of social support can have a devastating effect. Services that offer respite for these parents such as school and home nursing are crucial to allowing parents to successfully care for their children at home. When these supports are removed, there may be no safety net for these parents, revealing the tenuous state of care for these children. While many parents are able to provide the intensive medical therapies needed, there is a feeling amongst HCPs that it does not take much for this care to be compromised. As we move forward through and beyond the COVID-19 pandemic, it is important that HCPs, educators, and policy makers recognize how fragile the situation can be for families of children with LT-CCCs, and to ensure that we build resiliency into our care system so that in future societal emergencies the needs of these families are not ignored. Our study suggests yet another vulnerability of our medical system that COVID-19 has laid bare (Blumenthal et al., 2020).

Our results also display how deeply connected to the medical community these families are, and how disruptions to this relationship can be dangerous. The COVID-19 pandemic made previously routine medical appointments substantially more difficult. This has the effect of distancing the families from their medical supports. This distancing was viewed by the HCPs interviewed to be concerning. Without the medical teams being able to closely follow and ensure that medical care was being properly provided, there was concern that things were being missed and that medical care was potentially sub-optimal. Although our study design precludes determining if medical neglect increased as a result of COVID-19, it clearly demonstrates that many HCPs were concerned that it did. This highlights how frequently and easily HCPs think about the possibility of medical neglect. For HCPs caring for children with LT-CCCs, concerns for medical neglect appear to be a consistent worry. These results again point to steps that
can and should be taken moving forward and beyond the pandemic. It is clear from our interviews, that HCPs view connectedness with the medical community as protective. A family that is well connected with their medical providers will be able to bring up medical concerns, ask questions when they arise, and discuss evolving goals of care. Similarly, the medical team will be more able to perform regular exams during, make changes as needed and ease the discussions around goals of care and expectations.

Finally, these interviews highlight the utility of telehealth. For children with LT-CCCs, the expansion of telehealth offers great potential in changing how care is delivered. Although telehealth cannot and should not replace in-person visits, it can expand the number of touchpoints that a medical team has with a family. For children who can decompensate quickly yet are difficult to transport, telehealth can offer a rapid way for HCPs to check in with families to determine the appropriate medical course. It would seem that for families of children with LT-CCCs, regular telehealth visits can substantially ease the burden of regular medical appointments while additionally offering a new avenue for voicing concerns and changes to the medical team.

This study has numerous strengths. The topic of medical neglect in children with LT-CCCs is not one that has been well researched previously. This study, therefore, represents an important and necessary step in understanding how outside forces, such as the COVID-19 pandemic, can impact concern for medical neglect in this vulnerable population. Additionally, the quotations used in the study came from a variety of sources, including all disciplines and teams included in the parent study. This suggests validity of the conclusions.

Our study has several limitations as well. As this is a qualitative interview study with HCPs, no conclusions can be drawn as to the true quantitative effect of COVID-19 on cases of medical neglect. However, as concern for medical neglect tends to be first raised by medical providers, this study does offer insight into how COVID-19 has affected that thought process. Eleven of twenty participants did not mention COVID-19. However, the interview guide was designed to allow interviewees to dictate the conversation. These were single non-exhaustive interviews. It is likely that the failure of a provider to mention COVID-19 likely reflects their prioritizing discussion of other facets of medical neglect in children with LT-CCCs. Additionally, the racial/ethnic and gender makeup of the HCPs in this study was homogenous. This is a result of the characteristics of the providers on the care teams in interest. Sampling was purposive with the goal of including varied roles and medical teams. Racial/ethnic and gender demographics were not included in the purposive sampling methodology. Finally, this was a single-center study possibly limiting generalizability. However, Boston Children’s Hospital is a high-volume referral center for children with LT-CCCs and providers likely have substantial experience caring for this patient population.

Conclusion

The COVID-19 pandemic has had a substantial impact on the care delivery for children with LT-CCCs. Through changes in family support and medical care delivery, the burden of caring for these children has increased. For children with very high medical needs, this contributes to a concern that the potential for medical neglect is higher and the ability to detect it is diminished. This phenomenon highlights the fragility of the care system for these children and suggests that change is needed if we are to best support families in caring for these children.

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