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Exploring the Impact of the Coronavirus Pandemic on Pediatric Palliative Care Clinician Personal and Professional Well-Being: A Qualitative Analysis of U.S. Survey Data

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Abstract

Context. The COVID-19 pandemic has had a dramatic impact on palliative care delivery and patient experiences. Less is known about the experiences and responses of palliative care clinicians.

Objective. We aimed to describe the pandemic’s impact on pediatric palliative care clinicians’ personal and professional well-being.

Methods. The Palliative Assessment of Needed DEvelopments & Modifications In the Era of Coronavirus (PANDEMIC) cross-sectional online survey was posted on 7 professional listservs between May and June 2020. We conducted a conventional content analysis of written responses to three open-ended questions regarding the lasting impact of COVID-19.

Results. Of 207 multidisciplinary respondents from 80 US cities, 148 (71%) provided written responses to open-ended questions, and 62 responses (42%) were related to personal, professional, or existential well-being. These responses were sorted into 4 major categories: personal burdens, professional burdens, personal benefits, and professional benefits. Respondents described burdens more commonly than they did benefits (67% vs. 33% of comments, respectively). Personal burdens related to increased fear and uncertainty, fear of bringing the virus home, and a sense of collective grief. Professional burdens included a sense of exhaustion, a challenge with work-life balance, personal experiences with colleagues infected with the virus, and considerations of leaving health care altogether. Personal benefits included lessons learned, an evolving sense of what matters, and improved work-life balance. Professional benefits included opportunities for professional development and a sense of professional purpose.

Conclusion. Pediatric palliative care clinicians perceive a breadth of impacts from the COVID-19 pandemic. Ongoing clinician assessment is important as the pandemic continues. J Pain Symptom Manage 2020; - e - C211 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
COVID-19, pediatric, resilience, burnout, work-life balance, professional, well-being

Key Message
In this cross-sectional survey of pediatric palliative care clinicians, responses to three open-ended questions reflected personal and professional burdens and benefits of the COVID-19 pandemic. Burdens largely reflected feelings of fear and uncertainty, challenges with work-life balance, and collective grief.

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Benefits included evolving lessons learned, professional development, and newly identified values.

**Introduction**

The coronavirus disease 2019 (COVID-19) pandemic has had profound impact on the palliative care community. Indeed, the *Journal of Pain and Symptom Management* dedicated an entire issue to the shared lessons learned so far, including how to consider palliative care clinicians’ roles and responsibilities, tools and techniques for communication and symptom management, as well as guidelines for inpatient and community-based response and triage of resources.1–7

The objective of the Palliative Assessment of Needed DEvelopments & Modifications In the Era of Coronavirus (PANDEMIC) study was to explore the experiences of pediatric palliative care clinicians and teams during the early weeks of the pandemic (Weaver et al., under review). In order to capture broad perspectives and key subjective lessons learned, we included several open-ended questions at the end of the survey. Upon review of responses, we noticed that a significant proportion of responses focused on personal and professional well-being, rather than palliative care practice implications. To our knowledge, the COVID-19 literature, to date, has not described palliative care clinician well-being directly. Hence, we conducted the present qualitative analysis to describe the personal, professional, and existential benefits and burdens of the pandemic, as reported by survey respondents.

**Methods**

The PANDEMIC study was a cross-sectional survey-based study of pediatric palliative care clinicians in the United States. Using the Tailored Method of Survey Design,8 we created a comprehensive survey consisting of 52 closed and 5 open-ended questions querying the ways the pandemic had impacted clinical care delivery, practice models, and clinician experiences. We reviewed, piloted, revised, and repiloted the survey with 8 pediatric professionals (2 physicians, 2 social workers, 2 nurse scientists, 1 chaplain, and 1 mixed methodologist). The Office of Human Subjects Research Protections at the National Institutes of Health determined that the survey format and content qualified as exempt from full Institutional Review Board review.

We posted the survey via SurveyMonkey and with permission on 7 US national listserves (the American Academy of Hospice and Palliative Medicine Pediatric Palliative Care Special Interest Group; the Palliative Care Research Cooperative Pediatric Group; the Hospice and Palliative Nurse Association Pediatric Special Interest Group; the Association of Pediatric Oncology Social Workers, the Social Work Hospice and Palliative Network, the Pediatric Chaplains Network, a professional Pediatric Bereavement Care group, and a clinical Child Life group). Pediatric clinicians were eligible to participate if they 1) identified themselves as a pediatric palliative care provider, 2) were able to read and understand the English language, and 3) believed their work had been impacted by COVID-19 in any way since the emergence of the pandemic. Between May 1 and June 26, 2020, each listserv posted one announcement and one follow-up reminder 7-14 days later. We also emailed the link and one reminder message to pediatric palliative care clinical faculty representatives at 10-20 programs from low, medium, and high COVID-19—burdened geographical regions based on the Johns Hopkins University Coronavirus Resource Center map distribution during that time period.9

Quantitative survey questions focused primarily on palliative care clinical practice, team structure, and care delivery before and during the pandemic. Of the 5 open-ended questions, 2 focused on these same domains. The other 3 were designed to be broader and asked, “Can you tell us about an experience you have had related to COVID-19 that you feel will stay with you, always?” “What is something you wish you knew/learned prior to the COVID-19 pandemic that might have impacted how you approached your personal/family life during the pandemic?” And, “Please take this opportunity to share any other ways your work has been impacted by COVID-19 that have not been captured in this survey.”

To analyze the open-ended questions, we first separated the free-text narratives into 3 classifications determined a priori: 1) the impact on pediatric palliative care clinical practice and team structure; 2) the impact on end-of-life care; and 3) the impact on personal, professional, and existential well-being. For the present analysis, we extracted responses related to the third classification from the aforementioned 3 broad question stems. Using a conventional content analysis with inductive category development,10 we first identified 4 major categories of data: personal burdens, professional burdens, personal benefits, and professional benefits. Then, within each category, we identified subcategories and defined them with quotes and key phrases taken directly from the data. Each respondent’s entry was considered a unique data-point except in cases where respondents wrote multiple sentences fitting multiple subcategories. In those cases, entries were split, by full sentence, to fit into corresponding subcategories. Each final data-

**Quantitative Results**

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### Table 1

The Impact of COVID-19 on Pediatric Palliative Care Clinician’s Professional and Personal Well-Being: Burdens and Benefits

| Domain                     | Burdens                                                                 | Benefits                                                                 |
|----------------------------|------------------------------------------------------------------------|--------------------------------------------------------------------------|
| Personal life              | • Increased fear and uncertainty \((n = 11)\)                           | • Things I have learned along the way \((n = 9)\)                         |
|                            |   ○ Constant change. Daily updates with dire theoretical possibilities |   ○ Further emphasized the importance of keeping personal life prioritized. |
|                            |   ○ Better understanding of our family’s differential need for social interaction and how hard it is when you disagree. In a pandemic where stay-at-home orders and social distancing are key, this can become a significant daily stressor. |
|                            |   ○ How to deal with anxiety of both an unknown infection as well as economic issues. |   ○ Good self-care and boundaries essential to doing really meaningful work for others! |
|                            | • Afraid of bringing it home \((n = 8)\)                               |   ○ Taking stock of what matters most \((n = 7)\)                        |
|                            |   ○ The anxiety about potentially bringing home illness to my family is not something that has ever been of particular concern, even with other outbreaks, i.e., H1N1, etc. It has been a worry with COVID-19. |   ○ Home grandmother died and I couldn’t be there, but the cousins used zoom to be there virtually and it was beautiful. |
|                            |   ○ I’ve also been really afraid of bringing it home to my family. I spent the first 4 weeks of this feeling like an atomic bomb around them. |   ○ There is still so much beauty and resilience in humanity, it stuns me. |
|                            |   ○ Collective grief \((n = 6)\)                                       |   ○ Better work-life balance \((n = 4)\)                                |
|                            |     ○ Collective grief experienced by the community.                   |     ○ That the time I spend traveling to and from meetings that will hopefully remain virtual is better spent at home with my kids. |
|                            |     ○ I would have asked my parents to be here for the duration ... I worry, although they are healthy now, that I may never see them again. |     ○ Even though I feel compelled to be helping others at the hospital, it is essential to spend quality time with my family. |
| Professional role & identity | • I’m exhausted \((n = 9)\)                                           |   ○ Opportunities for professional development \((n = 8)\)               |
|                            |   ○ Hardest I’ve ever worked in my life (including residency) given excess workload and home schooling. I’m exhausted. |     ○ COVID has stripped away my usual support structure and caused me to set up a more formal system within my work group. It has caused us to fall back on each other with words to realize how much we can support one another in this time of crisis. My group is amazing! |
|                            |   ○ Feel more mentally exhausted and have had to really focus on self-care and team care. |     ○ It has given me additional responsibilities in communication that have broadened my view and experience in caring for the entire family. |
|                            | • Life-work balance ... such a challenge \((n = 8)\)                  |     ○ Opportunities to focus on professional development. Reflecting on how we may continue to grow and build our PPC to continue to serve our patients/families and staff well. Focus on resiliency as a key to staying healthy & serving well! |
|                            |   ○ My academic productivity has been low. Clinical time has taken priority, and I’ve had to be at home more to help with my kids who are out of school. I have no childcare and a working spouse. That’s been really stressful. |                                                      |
|                            |   ○ Research has stopped. It has been exceedingly difficult to be creative and productive. There is such a difference in experience based on role within the team, family structure, and role within the family. |                                                      |
point was assigned to a single subcategory; where a data-point could fit into multiple categories based on context, 3 authors (A.R.R., M.S.W., and L.W.) determined its best fit by consensus.

### Results

A total of 210 pediatric palliative care clinicians (79 physicians, 40 nurses, 23 advanced practice providers, 19 chaplains, 17 social workers, 16 child life specialists, 5 psychologists, 3 bereavement coordinators, and 8 other roles) from 80 cities within 39 states and the District of Columbia responded to the survey. Of these, 148 (71%) provided written responses to the open-ended questions, and 62 of those responses (42%) were related to personal, professional, or existential well-being. These 62 responses were sorted into 76 discreet text data-points fitting within 13 subcategories (Table 1).

Respondents described burdens of the pandemic more commonly than they did benefits, and burdens were equally distributed between personal and professional domains (Table 1). Specifically, 51 (67%) comments reflected burdens, with 25 (33%) focused on personal and 26 (34%) focused on professional burdens. In contrast, among the 25 descriptions of benefits, the vast majority (n = 20, or 80%) focused on personal well-being. Taken together, more comments (n = 45,
or 59%) focused on personal well-being, compared to 31 (41%) focused on professional well-being.

Subcategories of personal burdens included feelings of fear and uncertainty, worry of bringing the infection home to loved ones, and a sense of collective grief for the changes and losses experienced by our larger society (Table 1). When describing what would always stay with them, for example, one person wrote about the “constant change” and “dire theoretical possibilities” associated with the pandemic. In response to how COVID-19 had impacted their work, another person wrote about the overlap between work and home life, saying, “I spent the first 4 weeks of this feeling like an atomic bomb around (my family).” When describing what they wished they had known before the pandemic, another person shared the angst of potentially not seeing loved ones again.

Professional burdens focused on a sense of exhaustion, challenges establishing work-life balance, and maintaining productivity while working from home (Table 1). “Hardest I’ve ever worked in my life … I’m exhausted,” wrote one person. “My academic productivity has been low,” wrote another, “… I’ve had to be at home to help with my kids … I have no childcare and a working spouse. That’s been really stressful.” Less commonly, respondents shared concerns for critically ill colleagues and the sense that they, too, could become ill in the workplace. In two cases, respondents shared considerations of leaving the field altogether. “I am not truly sure I can do this anymore,” said one, “I am sad a lot now, and though I find speaking with patients and families fulfilling and purposeful, it is no longer my passion.”

Personal benefits centered on positive lessons learned, an evolving sense of what matters most, and a new ability to achieve work-life balance (Table 1). “There is so much beauty and resilience in humanity, it stuns me,” one person wrote. Another noticed “the time I spend traveling to and from meetings that will hopefully remain virtual is better spent at home with my kids.”

Finally, professional benefits reflected the development of new skills and new perspectives. “COVID has stripped away my usual support structure and caused me to set up a more formal system within my work group. It has caused us to fall back on each other with words to realize how much we can support one another,” wrote one person. Another shared that the challenges posed by the pandemic had led to the development of new communication skills. Finally, another wrote “seeing families in their home setting under a stressful pandemic situation and how resourceful they can be” would stay with them, always.

**Discussion**

There is no doubt that the COVID-19 pandemic has changed the way we practice clinical palliative care—be it with telehealth, physical distancing, or new approaches to communication. What is less described is the direct personal and professional impact on palliative care clinicians. Indeed, while the aim of the PANDEMIC study was to describe how the field of pediatric palliative care was responding to the pandemic, survey respondents made clear that they, as individuals, were struggling, learning, and changing too. Specifically, they reported both burdens and benefits affecting their personal and professional well-being. Their words focused on a sense of collective grief and uncertainty, a lack of professional productivity, and challenges with work-life balance. A minority focused on more positive experiences, such as new perspectives about personal values and opportunities for professional development.

That the palliative care community articulated such universal stressors is not surprising. As a discipline, palliative care is particularly attuned to the holistic aspects of adversity. When it comes to serious illness, for example, we recognize that both personal and professional lives are impacted and need support. The findings of the present study underscore the fact that challenging experiences influence all aspects of our lives. Moreover, challenges in one sphere translate to challenges in others. The most self-evident example is the ubiquitous experience of working from home during COVID-19: Balancing professional demands, personal worries, and the needs of family has been challenging for many.

We in palliative care can also appreciate the simultaneous and sometimes contradictory experiences of distress and joy, or in this case, burden and benefit. We ask patients to identify their worries and hopes in the face of the adversity of serious illness; why should we not ask ourselves to do the same in the face of the pandemic? Our findings suggest pediatric palliative care clinicians are grappling with some of the same existential demands.

This cross-sectional study occurred among pediatric clinicians at a single time-point. This design element is important for four key reasons. First, the written responses likely reflect respondents’ predominant emotional or cognitive processes at that time; they do not capture the complete spectrum of positive and negative experiences. Second, our responses reflect clinicians’ perspectives within the first few months of the pandemic (May-June, 2020). Many communities had not yet seen dramatic rises in cases nor clinical burdens; we knew less about COVID-19 transmission and clinical outcomes then than we do now.
If we repeated the survey today, answers might be different. Third, while these narratives are from pediatric clinicians, they are unlikely to be specific to the pediatric field. They may instead resonate with health-care providers of all types, if not with the general public.

Finally, these responses illustrate the fact that different individuals respond to stress in different ways at different times. Consider again the experiences of patients and families. We anticipate their feeling distressed when faced with the demands of new serious illness. We know it takes time to accept and learn to navigate change. We hope they will acquire new adaptation skills with time. So too must palliative care clinicians experience stress, uncertainty, and fear when faced with something as important as a global pandemic. So too will it take time to accept and navigate this change. So too will they acquire new coping skills with time.

In these ways, our survey responses resonate with resilience theory. Resilience—the process of harnessing resources to sustain well-being in the face of stress—is evidenced by both the acknowledgment of stressors and changes and by the identification of existing values and new direction. Furthermore, resilience is not linear. At some times, it is characterized simply by getting through a day, while at other times, it necessitates deliberate reflection of lessons learned. Our findings suggest that pediatric palliative care clinicians, including those who are struggling or considering new careers, are resilient. (Experiencing burnout does not necessarily imply a lack of resilience; rather, it means that the burdens of the work persistently outweigh the benefits. Resilience is the capacity to weather and move on from that burnout.) Clinicians in our study are responding to the pandemic by considering what it means for their personal and professional lives. They are recognizing the challenges, and they are finding meaning and purpose however they can. For some, this might mean moving away from something that has become overly onerous. For some, it might mean changes within their personal or professional spheres. For others, it may mean doing more of what already fulfills them. Taken together, these findings inform future work for clinicians and health-care staff, including approaches to trauma-informed career counseling and professional resilience.

Several additional limitations of this analysis warrant attention. First, the survey asked nondirective questions about clinicians’ experiences; only a single question asked explicitly about personal/family life. As such, the responses are unlikely to reflect the full spectrum of pediatric palliative care clinician experiences. Second, we noticed a wide variety of comments suggesting we did not “saturate” our data as is standard for qualitative methods; we cannot be confident that these answers represent generally shared perspectives. Third, we did not link discipline or location of practice to responses, so we cannot determine if patterns of perspectives cluster based on the relative exposure or proximity to the virus. Similarly, we cannot know if respondents interacted directly with patients with COVID-19, changed their practice (e.g., to care for adult-aged patients), or had other clinical experiences or training to shape their answers. Finally, although we believe this is a representative sample of pediatric palliative care clinicians from across the United States, we cannot speak to the sample’s specific demographics or diversity because we did not collect such data.

COVID-19 will have lasting impact on clinical practice and individual well-being. In this first survey of pediatric palliative care clinicians’ experiences and perspectives early in the pandemic, respondents shared personal and professional burdens and benefits. Their responses likely reflect those of the general health-care workforce, if not the population at large. Burdens were related to fears of uncertainty and infection (both at home and at work), challenges in work-life balance, and a sense of shared grief and exhaustion. Benefits included the identification of new values and lessons learned (both about how to work and how to live). Time will tell how we as a society and individuals continue to adapt and learn.

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