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Gorbenko, Ksenia Franzosa, Emily Masse, Sybil et al.

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"I felt useless": a qualitative examination of COVID-19's impact on home-based primary care providers in New York

Ksenia Gorbenko, PhD^{a,b}, Emily Franzosa, DrPH^{c,d}, Sybil Masse, MPH^e, Abraham A Brody, MD^f, Orla Sheehan, MD, PhD^g, Bruce Kinosian, MD^{h,i,j}, Christine S. Ritchie, MD, MSPH^k, Bruce Leff, MD^l, Jonathan Ripp, MD^m, Katherine A. Ornstein, PhD^c, Alex D. Federman, MD^e aDepartment of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, New York, New York, USA

bInstitute of Health Care Delivery Science, Mount Sinai Health System, New York, New York, USA

^cBrookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York, USA

^dGeriatrics Research, Education, and Clinical Center (GRECC), James J. Peters VA Medical Center, Bronx, New York, USA

Department of Medicine, Icahn School of Medicine at Mount Sinai, New York, New York, USA

^fHartford Institute of Geriatric Nursing, Rory Meyers College of Nursing, New York University, New York, New York, USA

⁹Center on Aging and Health, Division of Geriatric Medicine and Gerontology, Johns Hopkins University, Baltimore, Maryland, USA

^hCenter for Health Equity Research and Promotion, Corporal Crescenz Veterans Affairs Medical Center, Philadelphia, Pennsylvania, USA

Leonard Davis Institute of Health Economics, University of Pennsylvania, Philadelphia, Pennsylvania, USA

^jDivision of Geriatrics, University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania, USA

^kDivision of Palliative Care and Geriatric Medicine, Mongan Institute Center for Aging and Serious Illness, Massachusetts General Hospital, Harvard Medical School, Boston, Massachusetts, USA

^ICenter for Transformative Geriatric Research, Division of Geriatrics, Department of Medicine, School of Medicine, Johns Hopkins University, Baltimore, Maryland, USA

^mDepartment of Medical Education, Icahn School of Medicine at Mount Sinai, NY, New York, USA

Abstract

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CONTACT Ksenia Gorbenko ksenia gorbenko@mountsinai.org Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, Institute for Health Care Delivery Science, Mount Sinai Health System, One Gustave L. Levy Place, Box 1077, New York, NY 10029-5674.

Research on professional burnout during the pandemic has focused on hospital-based health care workers. This study examined the psychological impact of the pandemic on home-based primary care (HBPC) providers. We interviewed 13 participants from six HBPC practices in New York City including medical/clinical directors, program managers, nurse practitioners, and social workers and analyzed the transcripts using inductive qualitative analysis approach. HBPC providers experienced emotional exhaustion and a sense of reduced personal accomplishment. They reported experiencing grief of losing many patients at once and pressure to adapt to changing circumstances quickly. They also reported feeling guilty for failing to protect their patients and reduced confidence in their professional expertise. Strategies to combat burnout included shorter on-call schedules, regular condolence meetings to acknowledge patient deaths, and peer support calls. Our study identifies potential resources to improve the well-being and reduce the risk of burnout among HBPC providers.

Keywords

COVID-19; well-being; burnout; health care workers; home based primary care; pandemic; crisis management

Introduction

The coronavirus disease SARS-COV-2 (COVID-19) pandemic has become a major health crisis with profound impact on patients afflicted by the disease, but also on those who care for them. As a new surge is underway, there is increasing concern about the stressors associated with COVID-19 and their effects on the mental health and well-being of frontline health care workers (Lai et al., 2020; Ripp, Peccoralo, & Charney, 2020; Shanafelt, Ripp, & Trockel, 2020). In the initial phases of the pandemic, these stressors were related to a fear for one's safety needs, the uncertainty of what was to come, and the grief from lost patients' and colleagues' lives (Ripp et al., 2020; Shanafelt et al., 2020). Following the initial wave, health care workers and organizations are taking stock of what they have experienced, reflecting on the loss, both personal and professional, and continuing to experience psychological consequences.

Elevated anxiety and stress levels among health care providers in hospital settings across the globe during COVID-19 have been documented (Adams & Walls, 2020; Bohlken, Schömig, Lemke, Pumberger, & Riedel-Heller, 2020; Lai et al., 2020; Preti et al., 2020; Zhang et al., 2020). Systematic reviews have noted that health care workers reported higher levels of anxiety, depression, and insomnia compared to the general population (Pappa et al., 2020; Vindegaard & Eriksen Benros, 2020). Yet few studies have evaluated the experience of frontline clinicians beyond the hospital or nursing home setting (Lai et al., 2020; McGarry, Grabowski, & Barnett, 2020). To our knowledge, there have been no such studies in primary care settings. Burnout is a psychological syndrome in response to prolonged stress that involves "emotional depletion, loss of motivation, and reduced commitment" (Maslach, Schaufeli, & Leiter, 2001). Maslach and colleagues describe three components of professional burnout in human services professionals: (1) emotional exhaustion (feeling depleted, unable to give of oneself psychologically); (2) depersonalization (callousness

toward patients, dehumanizing clients); (3) reduced personal accomplishment (evaluating oneself negatively in terms of professional work performance) (Maslach, Jackson, & Leiter, 1996). Professionals may experience one, two, or all three components of burnout.

One group for which there is growing concern in the context of the pandemic is home-based primary care (HBPC) providers, who care for vulnerable homebound adults with multiple comorbidities. HBPC is longitudinal primary care delivered to individuals in their homes by physicians, nurse practitioners, and physician assistants (PAs) with interdisciplinary care teams. HBPC has become a rapidly growing area of care delivery (Reckrey et al., 2020), emerging as a successful strategy for improving health outcomes for the homebound by reducing hospitalizations, improving quality of life for patients and reducing caregiver burden (Chang, Jackson, Bullman, & Cobbs, 2009; Decherrie, Soriano, & Hayashi, 2012; Edwards, Prentice, Simon, & Pizer, 2014; Eric De Jonge et al., 2014; Stall, Nowaczynski, & Sinha, 2014; Yao, Ritchie, Cornwell, & Leff, 2018).

HBPC providers often have long-term relationships with the patients they serve, serving as their clinicians for multiple years until death. It is unknown whether the unique and highly personalized care model coupled with the medically and psychosocially complex patients they care for puts HBPC providers at higher risk of burnout in the midst of stressful circumstances, such as a pandemic. Long-term relationships with patients and families could be protective for clinicians, while the challenge of providing good care while simultaneously experiencing the loss of patients could pose major stresses. The initial wave of COVID-19 infections in New York City lasted between March 16 (citywide school closure day) and the end of April, with peak deaths reported on April 8, 2020, when the city reported about one-fourth of all U.S. COVID-19 deaths (NBC New York, 2020; Thompson et al., 2020). During this surge, HBPC practices continued to provide care for patients despite devastating losses and inability to provide in-person care to many patients who were isolated and very ill (Franzosa et al., 2021; Groeger, Starrels, & Ehrlich, 2020). Lessons learned from a group of HBPC clinicians in New York City in the context of the pandemic may provide valuable insights for other HBPC practices across the country. The aim of this study was to examine the psychological impact of COVID-19 on HBPC providers during the first peak in New York using data from qualitative interviews with HBPC providers.

Methodology

Study design, setting, participants and recruitment

This was a qualitative study of HBPC providers on issues pertaining to HBPC provider wellness during the COVID-19 pandemic. We conducted 30–45-minute semi-structured interviews via Zoom teleconference software using an interview guide originally designed to identify barriers and facilitators of HBPC care delivery during the initial surge of the COVID-19 pandemic in New York City (Franzosa et al., 2021). We interviewed HBPC clinical/medical directors, physicians, program managers, nurses, and social workers from six programs in New York in April 27 – July 30, 2020.

We recruited providers using purposeful and snowball sampling. We relied on the study team's professional networks and HBPC professional associations to identify initial

contacts, with a goal of achieving diversity in practice characteristics, e.g. health system affiliation, for-profit status, private or public ownership, and number of patients served. We invited these initial contacts to participate in the study and asked participants at the end of each interview to refer colleagues within and outside their practice. We aimed to interview two-three people per practice.

Data collection and analysis

All participants provided informed verbal consent. Two authors conducted the interviews, which were audio recorded. All recordings were professionally transcribed. One participant per practice also completed a 10-item survey questionnaire about their practice's characteristics (size, ownership type, affiliation, etc.). The interview guide focused on the following broad domains: (1) barriers to providing patient care due to COVID-19; (2) practice adaptations and innovations; (3) recommendations to other practices (See Table 1 for domains and sample questions). Within these domains, we probed for how practices managed patient care, including end-of-life care, telehealth, community resources, and how these changes impacted providers. The theme of provider well-being emerged naturally in early interviews, as we asked participants to describe how COVID-19 affected them. We adapted the interview guide to allow for an in-depth exploration of this topic with participants. We encouraged discussions of participants' emotional state (e.g. feeling overwhelmed) by validating their feelings. Our interviews remained open-ended.

We field-tested and refined the interview guide in three pilot interviews with providers in the program. We included pilot interview data in our sample. We used a combined inductive and deductive approach to analyze the data and focused coding to answer specific research questions. First, two coders reviewed all transcripts and coded independently for the parent codes "adaptations" and "advice" with associated subcodes, developing the initial codebook based on regular discussions and analytic memos. We report findings based on this first round of coding in a separate article (Franzosa et al., 2021). Then, two analysts coded all data for "impact on providers," coding the data into subcodes as we identified new concepts. One analyst used the code book to guide their coding of the remaining interviews using Dedoose qualitative software. A second analyst reviewed all of the coding; the two analysts resolved disagreements about coding by discussion and consensus. The study protocol was reviewed and approved by our institution's Institutional Review Board.

Results

Participant characteristics

We interviewed 13 participants from 6 practices: 6 medical/clinical directors (MD), 1 program manager (PM); 3 nurse practitioners/nursing coordinators (NC); and 3 social workers/coordinators (SW). Participants had worked in their practices for a median of 12 years. Practices were primarily private, nonprofit and hospital-based, although we included two independent practices and one public hospital-affiliated practice. The median size of the practices prior to the pandemic (March 1, 2020), was 900 and ranged from 45 to 1,400 patients. [See Table 2]

Below, we organized the themes around two components of burnout, emotional exhaustion and reduced personal accomplishment. The third component, depersonalization, did not emerge in our data. See Table 3 for themes and representative quotes from participants.

Emotional exhaustion themes

"We're used to patients passing but not like this": the traumatic experience of losing many patients at once—Participants across roles discussed the rapid increase in volume of patient deaths. A director of nursing stated, "I think it's just an increase of patients passing away that we cared for ... such a long time because of COVID-19, it's hard ... we're used to patients passing away but not like this." Providers reported increased death rates that were three to four times their average before the pandemic. According to one clinician, "We have on average probably around two ... to three deaths a week. That's pre-COVID ... and [now] we [were] averaging 10, 12 every week for a while." A medical director at another practice reported, "We lost 30 patients to COVID in April alone. That was one patient a day dying. We have patient volume of 500 patients – that was almost 10% in one month. We're used to losing maybe two people. It's just the nature of what we do, but 30 that was unheard of." Some participants became tearful when reporting the sheer number of deaths they witnessed since the beginning of the pandemic. All felt compelled to explain that death and dying was a part of their normal work, but the numbers were staggering and difficult to process.

The difficult experience of losing many patients to COVID-19 was exacerbated by the fact that providers had known some of these patients for many years, visiting their homes and developing close relationships with them and their families. This may have made these losses more personal and difficult. A social worker stated, "You really get to know them, their family, and their story in both their greatness and their challenges. It's a real loss when people die." She added, "You're left with this feeling sometimes when they die. Well I really know them with all their warts and everything." The speed of the deaths compounded this loss, "They died quicker, and that was just more upsetting than anything."

Grappling with and processing grief

Providers spoke about grieving their patients but also having no space to properly process the deaths amidst the overwhelming demands of caring for their sick patients and concerns about their own families. As the interviews took place within a few short weeks of the height of the first surge in NYC, many participants were still processing the deaths. According to one clinician, "They're all going to die [at some point] whether [or not] we're assisting, right? Right now, it wasn't supposed to be their time." A social work supervisor described the grief, guilt, and anxiety during the height of the crisis,

Then, the weeks that followed virtually after was really a combination of dealing with extreme grief and loss from our patients, combined with the anxiety of the world crisis, combined with our co-workers and the team trying to treat patients effectively without seeing them, which we had never done. We hadn't had an effective plan and managing our own and each other's anxiety, both personal and professional.

Some practices were acutely aware of the burden of the COVID death toll on their colleagues. One practice held condolence meetings bimonthly, in which practitioners could talk with their colleagues about patients who died. During the height of the pandemic, the meeting frequency was increased to biweekly. The same practice also adjusted length of on-call time for its providers to reduce the volume of deaths each provider experienced. One nursing director described receiving informal peer support within her practice. Participants from practices with affiliations with academic medical centers also had access to formal behavioral health resources, which smaller independent practices were unable to provide.

Pressure to adapt quickly

Having to constantly reinvent their workflows was an overarching stressor of the pandemic for HBPC health care workers. According to a social work supervisor, "I literally felt like I was a hospice social worker ... on steroids because ... before you process or said anything, you were just on to the next step." While all health care workers likely experienced increased physical and emotional exhaustion, some demands on HBPC providers' time included tasks similar to the ambulatory care setting. For example, they had to consent all their patients to telehealth to be able to bill for those encounters, making "50 phone calls on a Saturday morning." Several practices reported proactively reaching out to their patients at the beginning of the pandemic to eliminate unnecessary visits (e.g., physical therapy), determine patients' needs and supports, and maintain care to keep them out of the hospital. One nursing coordinator said she wished she had more personnel to help her call patients. Because she was "the only person," she was only able to reach out to patients about once every two months. Many of these new endeavors to establish good care for their patients were completed during providers' time off, causing physical exhaustion over time. One clinician spoke of her experience on the frontlines,

Thinking back to it, I don't know how we did it and I did it, but it was like anything else when you're in it, you just go through it. You don't sleep at night and you just get through it, but then when you have to think about it months later, you don't know - it's hard even [to] put into words because it doesn't even feel like it's something that we got through. It's unimaginable when you're trying to explain it.

Providers commented on how the uncertainty around the disease required ongoing adaptations and learning. One medical director described creating weekly COVID education sessions focused on "diagnostic and treatment dilemmas." They asked providers to submit questions in advance in order to prepare, fearing they would otherwise respond "I have no idea" much too often.

Reduced personal accomplishment themes

Grappling with guilt about the care quality—Many providers reported feeling guilt about the quality of virtual care they were providing. Several participants mentioned feeling worried that they had missed symptoms or changes that they would have otherwise noticed, had they been able to visit the patient in person. According to a nurse practitioner, "Maybe if things were different and I was able to go in and make visits, I could pick up other issues quicker and they could have had more life to their life." Providers also felt guilty for being unable to test patients to confirm they had COVID-19 because there were no home

tests available. "We're talking to them on their phone as their caregiver was not doing well, letting them know that this may be COVID," a nursing coordinator explained.

Rapid loss of confidence in one's expertise

Health care providers reported feeling they were no longer experts because they were unable to solve problems that were routine pre-COVID. Even when patients presumably had COVID-19 and were placed in home hospice, "family members had to probably call 911 because the patients probably need to be taken to the morgue because the funeral homes were all overwhelmed." This was in stark contrast to the normal process in which HBPC clinicians were able to advise family members on the next steps after a client passed away at home (call the funeral home and "everything would be taken care of"). This made them feel incompetent in their work role, incapable of doing a good job. According to a nurse coordinator, "I've been a NP since 2002, and I just felt like I didn't know what I was doing. It's like, was I doing a bad job that I couldn't provide for my patients?"

Feeling useless

The pandemic caused disruptions to all systems, and providers reported feeling useless as they were incapable of completing routine tasks. Social work supervisors shared feelings of helplessness when it came to their patients. "It's trying to balance the concrete needs of patients and families with the emotional piece and just being there on the other end, but also like the challenge of feeling helpless because there really wasn't something good that you could do for them." A nursing coordinator reported feeling frustrated and useless in trying to provide care in the pandemic environment. "I've never said 'I don't know' and 'I'm not sure' so many times in my life. I've never said that so many times as during this time period. So it's just like there was a lot of that – I felt useless ..."

Discussion

During the first peak of the COVID-19 pandemic in New York City, HBPC providers faced an unprecedented set of challenges that caused many to experience physical and emotional exhaustion and diminished confidence in their clinical skills and ability to provide effective care. Although our study was not designed to assess burnout, our findings correspond to two out of three components of professional burnout as described by Maslach and colleagues, emotional exhaustion and reduced personal accomplishment (Maslach, Jackson, Leiter, Schaufeli, & Schwab, 2016) (Figure 1).

Compounding the emotional strain from death of their patients was an experience of helplessness among HBPC clinicians, which is consistent with observations of health care providers in other COVID-19 clinical contexts. Prior research shows that the level of control and autonomy is a major driver of well-being or burnout among health care workers, with less control corresponding to higher risk of burnout (Shanafelt & Noseworthy, 2017). Depersonalization, a third component of burnout, was not apparent in our data. In our study, providers across the board showed deep care and compassion for their patients and their families. We did not see gender differences emerge in our sample around this issue, contrary to findings in previous studies (Maslach et al., 1997).

Our study investigated (a) how well HBPC practices were prepared to face a surge in COVID-19 cases; and (b) what strategies that emerged during the COVID-19 pandemic to support clinicians' wellbeing can inform best practices to contend with future crises. The responses of the HBPC providers indicate that the practices were ill-prepared for the disruption caused by the pandemic. While the practices demonstrated an ability to adapt (Franzosa et al., 2021), providers reported feeling emotionally depleted. This experience is similar to what has been reported for health care providers in other clinical settings and across the world (Barello, Palamenghi, & Graffigna, 2020; Mohindra, Suri, Bhalla, & Singh, 2020).

None of the adaptations described by clinicians interviewed for this study, nor reported in other studies, address the experience of diminished professional confidence, i.e. being able to manage the demands of care delivery. Diminished confidence, at least in clinic-based primary care, is associated with greater clinician turnover (Apaydin et al., 2020). The longer-term implications of stressors experienced by clinicians during the pandemic are unknown but worthy of study, as they could influence decisions about incorporating disaster preparedness into HBPC program design. We have an ongoing longitudinal survey study that examines this issue under way.

Our participants identified several strategies for supporting clinicians and their emotional needs that arose during the pandemic and could inform best practices for HBPC programs elsewhere. These included reduced on-call time, more frequent meetings to process the loss of life, and increased telephone encounters to make up for the drop in home visits. Our participants also identified supports that were absent but needed, such as administrative support to field the dozens of extra calls.

Prior research indicates that the most effective solutions to professional burnout are at the structural rather than individual level (or a mix of multi-level solutions) (Green, Albanese, Shapiro, & Aarons, 2014). These may include providing sufficient staffing to accommodate redeployment, furloughs, and sick leave; sufficient protective equipment; access to needed supplies and technology (NIOSH, 2016); frequent rotations on-and-off service, and organizational support for self-care (Kavalieratos et al., 2012). Healthcare systems have begun integrating multifaceted wellness programs to support their clinicians (Ripp et al., 2020) Wei et al., 2020). Components of such programs include resilience training, screening for trauma and burnout, behavioral health hotlines, creation of respite rooms, peer support and others. Professional organizations, such as the American Academy of Home Care Medicine (AAHCM, https://www.aahcm.org/) and the Home-Centered Care Institute (HCCI, https://www.hccinstitute.org/), held many educational webinars specifically for HBPC providers, serving as key resources for smaller independent practices. Future research needs to examine supportive organizational and proactive policy-level solutions to improve well-being among health care professionals in COVID-19 hot spots.

This study was limited by recruitment of clinicians and staff from a small number of practices in a single geographic area. Participants in our study have worked for a median of 12 years in health care. Research shows that health care workers are more vulnerable to burnout during training and early in their career (Brower & Riba, 2017). This suggests that

practices with less experienced personnel should be even more proactive in their support of clinicians. Experiences with care delivery in other regions of the country, especially rural areas, could be different from that experienced by the clinicians interviewed for this study. Additionally, this study was not originally designed to examine provider well-being and lacks pre-pandemic data on burnout or emotional status of participants. Rather, the themes reported here emerged during interviews intended to examine how care was delivered to patients in HBPC during the pandemic. The study team modified the interview guide to probe these themes exhaustively. We did not, however, specifically ask providers about depersonalization or cynicism toward their patients because of their apparent emotional distress. Furthermore, participants did not complete the Maslach Burnout Inventory or validated scales of post-traumatic stress disorder (PTSD); therefore, we cannot definitively report whether and to what degree individual participants experienced PTSD or specific components of burnout. However, our participants' reports correspond to the existing descriptions of two of the three components of burnout.

In conclusion, clinicians and staff of HBPC practices in New York City during the height of the COVID-19 pandemic experienced unique challenges in caring for their patients. Similar to hospital workers, HBPC clinicians experienced the high mortality of their patients; and similar to office-based primary care, they had to deal with financial changes and adoption of new routines including transitioning to telehealth. The combination of these stressors led HBPC clinicians to experience a diminished sense of professional confidence. Long-term relationships with patients and families characteristic of HBPC and providers' familiarity with palliative and end-of-life care helped practices develop interventions such as condolences meetings. The findings reported here identify strategies that other primary care practices, including those for homebound patients, could employ to prepare themselves for COVID-19 surges or other crises.

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The other authors declare no conflict of interest for this article.

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Impact statement

We certify that this work is novel clinical research. To date, no study has specifically addressed the impact of COVID-19 on home-based primary care providers' well-being. Our paper adds to the literature by describing these providers' experience in managing care of vulnerable population of homebound older adults during a pandemic, and providing strategies for managing health care workers' well-being during this and future crises.

Gorbenko et al.

Emotional exhaustion

Losing many patients at once

Guilt over

Grappling wiith grief

Struggling to adapt quickly

Reduced personal accomplishment Guilt over failing to save patients and quality of virtual care

Losing confidence in one's expertise overnight

Feeling useless

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*Our data had no themes related to depersonalization.

Figure 1. Themes mapped onto components of burnout (Maslach et al., 2006).

Table 1.

Interview guide domains and sample questions.

Domain	Sample questions	
Patient Care	What are your priorities for patient care?	
	How are you managing in-person visits?	
	What types of concerns are you seeing from patients and caregivers? How are you addressing them?	
	Have you had many COVID patients? Thinking specifically about your patients who have confirmed or suspected COVID-19, how have you managed their care?	
	Where are you receiving guidance on infection control? How are you following it? (Use of PPE, staff exposure, quarantine time)	
End-of-Life Care	How are you managing end-of-life care? (Goals of care and end-of-life conversations, advance care planning, access to opioids, symptom management, caregiver support, coroner/funeral homes)	
Telehealth	Did you or any of your colleagues use telehealth before the pandemic? Is your program using telehealth now? How did you manage the transition?	
	Are you finding there are limits to telemedicine? What are you missing in your telemedicine visits? What have you gained from telemedicine?	
Community-based resources	What community resources did your patients rely on pre-pandemic? (e.g. VNS, nursing staff, home health aides, meals on wheels) Are these resources still available for your patients?	
	What adjustments did you have to make to provide the needed resources to your patients?	
Staffing	Tell me about the staffing situation since the beginning of the pandemic? (e.g. staff and PPE shortages) How are you managing this situation?	
	How is your staff feeling about working in this environment? (burnout, preventive strategies)	
	What types of concerns are you seeing from them? What types of resources or support are you providing? (mental health support, structural support, e.g. PTO, leave, health insurance, unemployment)	

Table 2.

Program and participant characteristics.

Participant characteristics	N
Total participants	13
Role	
Medical/clinical director	6
Program manager	1
Nurse/nursing coordinator	3
Social worker/social work coordinator	3
Years working in program	
Mean	11
Median	12
Range	1–18
Program characteristics	N
Total Programs	6
Area served	
Urban	5
Suburban	1
Primary sponsor/owner	
Health system	4
Independent provider/group	2
Profit status	
For-profit	1
nonprofit	5
Sector	
Private	5
Public	1
Daily patient census before 3/1/2020	
Mean	811
Median	900
Range	45-1400
Years in existence	
Mean	13.5
Range	1–25
Participants interviewed per program	
Min	1
Max	4

Table 3.

Themes and sample quotes.

Themes	Sample quotes		
Too many deaths	"The deaths were so great in a very rapid pace. That was the quickest change in the shortest amount of time."		
Grappling with grief	"You really get to know them, their family, and their story in both their greatness and their challenges. It's a real loss when people die."		
	The big thing that has really impacted the staff, not only the social work staff, but the staff, as a whole, has been the deaths. That's been hard."		
Pressure to adapt quickly	"It's forced us to pivot a lot. This came on us like a bolt of lightning. To be honest with you, we didn't see it coming and we weren't prepared. I don't think anybody was prepared for it."		
Guilt about care quality	"I felt bad. I felt so bad that as far as the patients were getting sick it seemed like it was so different, the deaths anyway."		
	" we know we work with a very advanced ill population and we're probably going to see them die. They're all going to die whether we're assisting, right? Right now, it wasn't supposed to be their time."		
Rapid loss of confidence in one's expertise	"I've never said 'I don't know' and 'I'm not sure' so many times like in my life. I've never said that so many times as during this time period. So, it's just like there was a lot that – I felt useless. I feel like sometimes treating some of these patients like I feel like – I've been an NP since 2002, and I just felt like I didn't know what I was doing. It's like, was long a bad job that I couldn't provide for my patients?"		
Feeling useless	" when I spoke to one of the providers, I was like, "Well, I felt useless because this is what happened."		
	It's trying to balance the concrete needs of patients and families with the emotional piece and just being there on the other end, but also like the challenge of feeling helpless because there really wasn't something good that you could do for them."		