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Hospice and COVID-19

HIGHLIGHT

For a profession whose mission is to help terminally ill patients plan their final days and guide them and their loved ones through the passage emotionally and spiritually, a global pandemic presented the ultimate challenge. ASPR TRACIE met with Sarah McSpadden, RN, MSN, MHA, President and Chief Executive Officer of The Elizabeth Hospice, to learn more about her experiences during the COVID-19 pandemic.

ASPR TRACIE

Sarah, can you please tell us more about your work and the clients you serve?

Sarah McSpadden (SM)

Our mission is to enhance the lives of those nearing the end of life's journey and to care for those who grieve. As a community-based organization, we ensure that hospice care, palliative care, and bereavement support are available for all who face advanced serious illness. Our Elizabeth Supportive Medical Specialists provide personalized medical care for adults and children who need palliative support. The Elizabeth Hospice is one of the few organizations across the nation with a dedicated team specializing in perinatal and pediatric hospice. Our comprehensive grief support program serves families from the community no matter how their person died or whether their person was on service with us.

We were founded in 1978 when hospice was an all-volunteer program. In 1982, there was a significant shift: hospice became Medicare-reimbursable and we could hire permanent staff. Since that time, we have emerged as the largest nonprofit hospice provider in California, with five locations that serve San Diego County and Southwest Riverside County. Our two children's grief centers offer peer support groups at our facilities, and we conduct on-campus support groups in 20 school districts for grieving students. Over the years, our programs and services have touched the lives of more than 115,000 people.

Related Resources

- COVID-19 Home-based Healthcare and Hospice Resource Collection
- Engagement of Home Health and Hospice Agencies in Medical Surge Activities
- Homecare and Hospice Topic Collection
- Medical Surge and the Role of Home Health and Hospice Agencies (Full Report)
- Hospice and Emergency Preparedness: Experiences from the Field

People tend to think that patients receiving hospice care must live in a hospice house or a private home, but our service is more encompassing than that. Hospice care is provided where the patient resides ─ in a facility (a hospital system, post-acute care, assisted living, skilled nursing facility, (SNF) – or in the case of a homeless patient who I visited ─ in an avocado grove. More than 45 percent of our patients reside in skilled nursing and assisted living, two hotbeds of COVID infection.

The Elizabeth Hospice is an extensive, multidisciplinary healthcare delivery organization that serves 550 hospice patients and more than 100 palliative care patients daily. Currently, we have 17 pediatric hospice patients and several pediatric palliative care patients.

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How has COVID impacted you and changed the organization?

SM

The impact of COVID on our organization has been multifaceted. At the onset of the pandemic, one of our priorities was strengthening our communication channels to ensure continuous delivery of high-quality care. Interdisciplinary teams began meeting daily to discuss COVID-related challenges encountered in the field as well as support each other during these stress-filled times. We adjusted our communication patterns as we became more proficient in addressing COVID challenges. The daily meetings gradually became weekly and have now returned to bi-weekly sessions.

It was also necessary to put additional emphasis on internal communications. I held daily video conference calls with the staff to keep them informed of the latest organizational information. And we immediately formed a COVID task force to review local, state, and federal statistics. The task force produced a newsletter, the Corona Corner, to keep our staff well-informed and prepared for our patients' needs.

As a precaution, we arranged to have indirect staff work remotely. To accomplish this, we conducted in-home evaluations and added internet services where necessary.

Our five locations are administrative offices where field staff work close to their patients' locations. For the first six months of the pandemic, our three smaller offices remained closed. Our corporate office was at 50% capacity, with all senior leadership remaining onsite for the entire period. We established safety precautions for entering and exiting the buildings. These precautions included temperature checks taken electronically for everyone entering the building, answering screening questions, and keeping a log of people on the premises.

I am proud to say that there were no disruptions in our hospice or palliative care services during COVID.

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Did you have enough personal protective equipment (PPE) for staff? If not, how did you acquire more?

SM

We changed our infection control measures and equipped our staff with additional supplies to ensure their safety. Initially, it was challenging to get PPE; however, we worked with our suppliers and community contacts to solve this issue. Staff worked remotely in many different locations requiring them to change PPE frequently because each site has different standards. For example, our employees who had been issued masks at a hospital were not allowed to use that same mask at the next facility they visited.

All our field staff were fit-tested and given N95 masks. We have a fit-tested team who typically works with tuberculosis (TB) patients, so we already had a contract with a fit-testing company. That said, fit-testing 200 staff members had an impact on our budget.

Hospice was not included with hospitals and skilled nursing facilities as one of the initial types of healthcare organizations slated to receive PPE, so we had to get creative. Our regular medical supply company ran out of N95 masks but gave us KN95 masks (which we could not fit test). In some situations, our staff wore face shields and surgical masks while others wore fit-tested masks. At one point, we received a donation of PPE from the community and volunteers sewed masks for our non-clinical staff. We also purchased goggles from the local hardware store to help protect staff.

I think most hospices across the country struggled with a scarcity of PPE because there is a lack of understanding surrounding our work. The National Partnership for Hospice Innovation tried to buy PPE in bulk, but the shortage was worldwide. Fortunately, our emergency plan focuses on long-range goals, so we had enough supplies for a few months until PPE was more readily available.

Thankfully, we received CARES Act funding, which allowed us to buy UV wands for our staff to disinfect their equipment, cars, and bags to prevent infection from one patient to the next. The use of wands also allowed staff to disinfect their masks to wear them more than once safely.

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Did you receive assistance with bulk buying or other help from any national groups?

SM

There are several national hospice groups. I serve on the board of one of them ─ the National Hospice and Palliative Care Organization (NHPCO). This group was phenomenal in helping us meet our needs during the pandemic. Their meetings with the White House administration and with CMS were instrumental in driving regulatory changes that made it possible to move to a telehealth model. The National Partnership for Healthcare and Hospice Innovation (NPHI) also was involved in ensuring we had adequate PPE and sharing promising new care practices.

Even though hospice employees are frontline workers who enter acute care facilities, they were not included with the first tier of healthcare providers eligible to receive vaccines. I had a tough time getting my staff vaccinated (we were in the 1B tier). The authorities who established the tiers failed to recognize that hospice providers enter acute care facilities where they are significantly at risk of being exposed to the virus. NHPCO and their Hospice Advocacy Network, NPHI, and others were instrumental in getting our staff vaccinated. About 69% of our staff are fully vaccinated. Those who are not vaccinated either cannot or are holding off for religious or health reasons.

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How did staff feel about having to wear PPE and wand their equipment? Were patients concerned at all?

SM

We did have some staff who were afraid to go into facilities to visit patients because they were concerned about being exposed to COVID and bringing the virus home to their family. There were also patients afraid of staff coming to see them—especially in skilled nursing and assisted living facilities. The facilities started limiting visitation, affecting the amount of in-person work we were able to do.

Most of the time, our registered nurses (RNs) could visit; however, many facilities restricted visits from spiritual counselors, social workers, and home health aides. Those three disciplines are a vital part of hospice care. They provide invaluable support and manage the mental health of our patients and their loved ones. We noticed that the pandemic took an emotional toll on many patients and their loved ones.

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How did the restrictions on visitation affect your staff and patients? How did you change the way you communicated with patients and family members?

SM

Visitation restrictions made it difficult for clinicians to communicate with patients, patient families, and facility staff. We used telehealth and Zoom to facilitate communication. Both were instrumental in helping us overcome communication barriers. We received grant funding that made it possible to implement telehealth with biometric equipment so that staff could assess breath sounds as well as abdominal sounds at a central location. Centralizing these assessments enables both clinical and non-clinical staff to visit all our patients in a facility, then virtually connect with a group of providers to discuss care.

We had quite a few COVID-positive patients in hospitals where our staff were the conduit between the family standing outside the building and the clinicians inside. They met with the family to review consents for hospice and talk about goals of care based on what the patient and family wanted, then met with the hospital team to implement the plan of care.

At one point, we were admitting a COVID-positive patient and were trying to reach the spouse to arrange a meeting. As it turned out, the spouse was in the process of being admitted to the emergency room for COVID. The family had to plan for their parents' deaths simultaneously, standing outside of the hospital, while our staff coordinated with the in-hospital care providers.

Isolation added another level of complexity to the wide range of emotions that patients and their loved ones experienced. Our social workers and spiritual counselors who traditionally provide emotional support could not enter the facilities. The inability to be there in-person for their patients and families took an emotional toll on our staff.

Staff experienced compassion fatigue, which affects their emotional and physical well-being. We ensured our staff had access to our employee assistance program. Fortunately, the Ellen Browning Scripps Foundation funded a series of compassion fatigue workshops for our teams. These workshops helped staff build resiliency by teaching them self-care techniques and allowing them to talk candidly about their experiences. In hospice, you might lose a patient a day; but, our staff was losing 10-15 patients a week during the pandemic. The stress of possibly taking this infectious disease home to family members added to the enormous pressure they were already feeling.

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Will you continue to use some of the virtual reality/biometric equipment going forward?

SM

Moving to the future, virtual reality and biometric equipment will be part of our care. The Centers for Medicare & Medicaid Systems (CMS) adjusted very quickly and allowed hospice to do things that we had never done before. For example, one of the CMS rules that applies to hospice is the requirement that a medical provider has a face-to-face encounter with patients to determine if they are terminally ill. At the start of the pandemic, nurse practitioners were doing what I call "drive-by face-to-face encounters." They would meet patients outside or at the front door to discuss their current health status and review medical history; if possible, get a visual assessment to determine if they qualify for hospice. Once CMS agreed that telehealth could be used for the visual evaluation, it shifted our program to virtual face-to-face meetings since patients and loved ones did not want people entering their homes. The CARES Act funds we received helped to purchase technology that made it possible to work with patients and their family members virtually.

> ***We were able to acquire virtual reality equipment. Our nurses took that into patients who used the equipment to take "trips" around the world to places they had always wanted to see before they died.***

I anticipate we will continue utilizing these technologies, but typically, hospice is more acceptable in person because of these conversations' intimate nature. Our goal is to do most of this work face-to-face but use telehealth when this presents a risk to the patient or our staff. Technology also helps us connect to patients in more remote locations, particularly when a time-sensitive response is needed.

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How do you get referrals? Were you able to accommodate them all during the surges?

SM

We typically receive referrals from all healthcare areas, and sometimes a family member will call us when a patient gets a terminal diagnosis. In one month last year, we had 17 patients transfer into our hospice from other hospices operating with limited staff because many had taken off to provide childcare and or eldercare. We were able to help at first because we had more staff to draw from.

Another challenge was that COVID clinics, vaccination sites, and COVID-specific hospitals paid higher wages to attract healthcare workers in high demand. While our staffing was declining, our referrals were increasing, so telehealth helped. There were times where our RNs, who typically carry 12-15 patients each, were carrying close to 25 patients with support from licensed vocational nurses.

Hospice also has a robust volunteer program; in fact, hospice was an all-volunteer service until CMS began reimbursing providers in 1982. Today, the federal rule is that 5% of the hours spent providing clinical care services (administrative and direct patient) must be provided by volunteers. We typically have a 10-15% volunteer staff, and most of these are patient care volunteers who visit with patients in person. COVID caused this to decrease so that we are barely above 5%. Currently, we have between 400-500 volunteers and continue to recruit them during the pandemic successfully. They are an essential resource for our staff. Volunteers telephone patients, read books to them, perform music for them, check on supplies, and address their emotional needs.

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What were some of the issues you dealt with regarding discussing and documenting end-of-life wishes?

SM

Our social workers and spiritual counselors spend a lot of time talking to patients about goals of care and the importance of documenting their wishes (e.g., physicians' orders for life-sustaining treatment). We ask patients to think about what is important to them and encourage their loved ones to be part of the conversation. Social workers help facilitate these discussions. We also encourage patients to complete an advance directive, including questions about eating in their final days and determining whether they want visitors or total privacy. We also help them plan their funeral arrangements prior to death.

During COVID, the conversations have been very different, mainly because our social workers cannot meet with the patient and family at the same time. We are essentially telling family members what their patient on a ventilator said (sometimes using sign language or asking them to respond by blinking their eyes). Further, we often had to work through the decisions very quickly due to the disease progression.

Before COVID, we would facilitate EMS transport and patient discharge from the hospital so they could be extubated/taken off a ventilator and die in the place of their choice. During COVID, the patient is extubated in a hospital setting after a conversation with the patient's loved ones. Staff would explain the process and how long it typically takes to pass after extubation. Our grief counselors are available to support families throughout this journey.

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How were your palliative care consultants used differently during COVID-19?

SM

Our community-based palliative care program has received far more referrals because more non-COVID patients are being seen in clinics and doctors' offices to avoid hospitalization. Our internal palliative care team works as hospitalists and saw their consultations increase dramatically. Our providers, who usually worked Monday through Friday, with two-three consults a day, shifted to working seven days a week, sometimes conducting five or six COVID and regular consults a day.

When patients are discharged from the hospital, our care team, which includes the palliative care team, follows up with them to reduce hospital readmission. They spent the year serving as a conduit between patients and primary care providers (who were overwhelmed), working in conjunction with their primary care provider to manage patients' symptoms. Every palliative care program has its unique qualities. There is typically no reimbursement for these services. The hospice and palliative care industry is working with CMS to put some standards in place around the country. Palliative care reduces readmission rates, and thus the overall cost of healthcare, tremendously, so it would be beneficial to standardize palliative care and have CMS reimburse it.

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What would you like hospice and palliative care to look like five years from now, based on the lessons you learned?

SM

I would love to see a coordinated effort around regulations for hospice and palliative care. This effort would make it possible to pull national data to determine our impact on the people we serve and lead to a more consistent care model. There are currently discussions centered on the value-based insurance design (VBID) model and the direct contracting entity model. Both would change the way hospice looks and functions. The goal is to improve the patient/family experience by establishing a Serious/Advanced Illness Care Continuum in place of segmented care.

Over the next five years, I would like us to identify a continuum of care that puts the patient in the center and coordinates care across all aspects of healthcare, allowing us to focus on outcomes and the desires of the patient/family. I would encourage access to palliative care and hospice earlier in the terminal diagnosis. Many patients are seen by multiple providers, leading to fractured uncoordinated care. A palliative care-trained provider could coordinate this work, summarize the medical information, and present options to the patient and their loved ones, facilitating a more informed process and a better experience for the patient and the family.