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COVID-19 Resources and Accomplishments

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2020: A year we will remember

We stand on the side of humanity. Always. 2020 has been a doozy so far. COVID-19 exposed not only gaps, but also inequities in our health care system. We must recommit ourselves to creating a fairer and more inclusive health care system. And now, as our new reality sets in, we are forced to face another uncomfortable reality: for many people, health care is just more of the same. The same systemic problems that cause some to get more care and others to need more care have led some—poorer, darker—to be harmed by the very people they pay to protect them.

What happened to Mr. Floyd in Minneapolis was not rare. What is rare is that it was caught on camera. I know that as President & CEO of the National Hospice and Palliative Care Organization, I should stay in my “lane”. But isn’t palliating suffering my lane? When somebody – or even worse, some group— dies in pain, hastened by government action, isn’t it my job to call it out? I think it is. We talk a lot about thought leadership, and often use the term to expound upon the most recent payment model. Tonight, I don’t feel like expounding upon that. Not when so many people are hurt and hurting. It is a raw time, and tensions are high. I want to be clear that this is not a partisan call. There is no Republican or Democratic way to be human. No conservative or liberal way to abide by the golden rule. We are all brothers and sisters, and the sooner we start acting like it the sooner we will get the health care system we all deserve.

We have been through tough times before, and we will go through them again. But we must make sure that we don’t let these moments pass or turn our heads thinking, “someone else should deal with the problem.” At the core of our hospice philosophy is the inherent dignity of every individual – those we care for and those we do not. Whatever we do, let’s make sure that we call out hate, heal suffering, and always stand on the side of humanity.

Edo Banach, JD,
President and CEO
NHPCO Delivers for Hospice and Palliative Care Community
Since the outbreak of the Coronavirus (COVID-19) crisis, NHPCO has been working as an effective advocate for hospice providers. Through the development of resources, near daily COVID-19 Updates, hosting of education webinars, pushing for policy support, and summarizing information from a range of sources, NHPCO has been committed to helping the hospice and palliative care community make it through this unprecedented public health crisis. NHPCO’s activity relating to COVID-19 has been a part of our leadership within our provider community and we hope some of the things we have created and accomplished have made a difference for hospice and community-based palliative care organizations in the U.S. Below, we highlight some of our accomplishments from the past few months.

POLICY ACCOMPLISHMENTS

Each of the following policies are the direct result of NHPCO’s work with Congress and the Administration.

CARES Act

Face-to-Face. Statutory change to allow use of telehealth technology for face-to-face encounters for recertification for hospice care, during the emergency period.

Sequestration Relief. These provisions eliminated the 2% reduction in Medicare reimbursement that has been in place since 2014.

Emergency Support Funding. Ensured hospices were included in the emergency funding provided under the CARES Act. Hospice was awarded $1 billion out of the first $30 billion of CARES money that was appropriated to health care providers. Hospices received grants based on their 2019 Medicare reimbursements.

1135 Waivers

NHPCO advocated for increased flexibility through 1135 waivers, including six separate 1135 blanket waivers recently approved by CMS. The waivers include extending the timeframe to update the comprehensive assessment from 15 to 21 days and waiving the requirement for onsite visits for hospice aide supervision.

Virtual Visits

In addition to the 1135 blanket waivers for hospice, NHPCO advocated for clarifications and flexibilities for hospice providers in delivering routine home care through the use of telecommunications.

FOCUSED EDUCATION

NHPCO has organized and hosted webinars focused on COVID-19 relevant topics including the latest updates, telehealth and virtual visits, and a series on compliance issues related to government funding. Webinars have been made available to the entire provider community while special-focused topics have been made available exclusively to NHPCO members.

COVID-19 UPDATES

NHPCO’s COVID-19 Updates offered breaking news and relevant links to timely information. As available information expanded or changed – on what seemed like a daily basis – NHPCO established this email that was sent on just about a daily basis to help providers in the field cut through the torrent of information that has been released. Available to members and non-members, the COVID-19 Update was part of our organization’s effort to keep providers up to date.

SOCIAL MEDIA

#hapcFacesOfCaring

NHPCO’s latest social media campaign #hapcFacesOfCaring highlights the faces and stories of hospice and palliative care teams providing care amid COVID-19. See page 34 in this issue of
NHPCO staff have worked with hospice experts in the field to develop content that is relevant and timely.
Professional education and training for staff and volunteers is an ongoing commitment that must be part of an organization’s culture. High-quality care, regulatory compliance, and clinical excellence require ongoing education. VC20 will balance both the clinical perspective and the programmatic perspective of quality.

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A Discussion on Effective Virtual Visits

Insight from Across the Interdisciplinary Team
NHPCO, in collaboration with the National Coalition for Hospice and Palliative Care, hosted a free webinar for the provider community on April 27, 2020. The idea for this webinar, COVID-19 Discussion on Effective Virtual Visits, emerged during a coalition quality work group call where the issue of quality virtual visits was first raised by representatives of the National Coalition.

In welcoming the national audience, National Coalition President and CEO Amy Melnick said, “It has been extraordinary to see how hospice and palliative care providers have responded to the COVID-19 epidemic with creativity, innovation, and of course compassion, which is the hallmark of the profession.”

Melnick continued, “For some on our faculty, they’ve been doing these types of visits using audio and video technology for years and have excellent outcomes and have wondered why the rest of the world has not provided care in this way, but for others, COVID-19 has presented a situation where providing care in this way is a necessary option due to safety and it’s becoming more normal, so to speak.”

Introduction

Coronavirus (COVID-19) has thrust us into some unchartered waters and has also allowed for some new opportunities. Opportunities to do remote visits for our patients and their families, protect them, protect health workers, and protect our limited supply of PPE.

There is a new opportunity in hospice and community-based palliative care to use telehealth for the face-to-face visit and for visits by the interdisciplinary team. Telehealth has always been available but now can be done on a more widespread basis than ever before. Also, this is a great opportunity to use telehealth for advance care planning and POLST completion, especially for the vulnerable seriously ill population.

NHPCO encourages providers to think about the long-term uses of telehealth as well as the short-term opportunity. It is also important to think about HIPAA compliant platforms if you are considering a possible expansion of telehealth for long-term use with your patient population.

Telephonic visits for billable providers are now reimbursable, which before they were not. While there has been expansion of waivers and relaxation of regulations at the federal level due to the COVID-19 crisis, you still need to be mindful your state regulations. NHPCO stresses the importance of making sure that you follow the most stringent rules, regulations and laws.

Definitions

There are many definitions and providers will hear a lot of terms like synchronous versus asynchronous, audio versus audio-visual, remote patient monitoring, digital health, and telemonitoring. Here are two definitions to remember:

- **TELEHEALTH** is a broader term used for the provision of health care remotely, whether you are using the simplest form, a telephone, smartphones, mobile wireless devices, with or without a video connection. Telehealth includes both clinical and nonclinical interactions.

- **TELEMEDICINE** is a term, specific to clinical visits with video/visual connections.

Webinar participants were asked about their practice.

**QUESTION:** Are you utilizing telehealth?

**ANSWER:** 53% yes in hospice care only. 36% yes in both hospice and palliative care. And 7% no.

**QUESTION:** What is the biggest barrier you are experiencing or that you perceive in providing tele health?

**ANSWER:** 26% support in the home. 14% functional ability. 13% connectivity. 10% equipment.
The panel reflected a diversity of experiences, locations, and discipline perspectives. Not all members of the interdisciplinary team are reflected in the following excerpts but a number of NHPCO COVID-19 focused webinars and chats have been provided in recent months that can be found at nhpc.org/coronavirus and within the MyNHPCO e-community for members.

Joe Rotella, MD, MBA, HMDC, FAAHPM

Joe Rotella is a Palliative Care Physician and Chief Medical Officer for AAHPM.

With telehealth, we need to think about having different approaches for different problems. We must think about how we can include the patient and family more in this partnership in their care. And COVID-19 has added an increased dimension to this because it’s not just the burden for the patient and the family to travel, but it’s the fear they might have that you would introduce infection if you come into their home.

There is also the fact that you would have to use personal protective equipment that might be better used in other instances.

**What We Hope For...**

We hope that we will see less actual spread of COVID-19 by utilizing telehealth. By not making any more in-person visits than are necessary we are helping with the distancing that is going to flatten the curve for everyone and we can conserve our limited supply of personal protective equipment.

Hopefully, this results in fewer hospitalizations and emergency department visits. We hope that we can improve quality through more timely intervention and see a high level of patient and family satisfaction. We hope to find that telehealth can improve access, particularly for people that are hard to get to and/or in remote rural areas, and that we can maximize cost efficiencies by eliminating things like windshield time, allowing us to spend most of our time doing what clinically matters.

**Effective Visits**

When we think about what makes an effective virtual visit, the ideal is to use both the audio and visual components. There is something you gain from being able to see the patient, to see them in their environment, to read body language and there is something they gain from being able to see us. Whenever possible, adding the visual component means you are going to have more rich flow and exchange of information; however, there may be times when that is limited due to connectivity issues or the availability of equipment.

The seriously ill population is a particularly good target for virtual visits because of the burden they feel in having to travel to a physician’s office or a hospital, having to wait in a crowded doctor’s office which increases their risk of exposure, and increased fatigue from travel. These burdens are much higher for the seriously ill.

**What Triggers an Interaction**

If you were to think about what might trigger a home visit or what might trigger a telehealth intervention, there is a broad number of things that could be the trigger. We can begin with just a simple acute issue. The patient has a new symptom, or in the COVID era, that symptom might be cough or infection, delirium might be a tip off that the person is coming down with COVID-19. COVID-19 screening can go all the way from the person who says, “I think I was exposed,” to the person who says, “I think I have symptoms,” to the person who says, “I’m very ill.”

We can think about advance care planning and goals of care discussions in general for anyone with serious illness, but also in the
context of COVID-19, it might be a somewhat different discussion than what would you do if you had cancer for a few years and you weren’t getting better. This is a different circumstance. See the NHPCO COVID-19 Shared Decision Making tool.

A virtual visit could be triggered by the need for a follow-up that could be required under your hospice conditions of participation or just good medicine. It could be time for a monthly check in or it could be to manage symptoms or to coordinate care. It could be for psychosocial or spiritual counseling. It could be to hold a family meeting with family members that are in different places. It could be to provide feedback, education, and support to caregivers.

And it can be used not only for patient and family interaction. It could be team meetings, it could be because we have information we need to give out around some change in policy and how we are delivering care, for example. Or it could be education.

**Back in 1998,** the University of Kansas worked with a local rural hospice provider to do a pilot telehealth demonstration project. It did not take off. First, it was expensive to do; technology cost more back in 1998 than it does now. And there were attitudes about technology that made it hard for patients and families and staff to adopt.

When they repeated the demo in 2017, they used mobile tablets and cloud-based video conferencing. They used it for direct patient care. They used it for family support, and they used it for administrative encounters including things like interdisciplinary team meetings.

What they found from the staff was this was seen as strengthening communication and strengthening relationships among patients, family, and staff. And it saved the hospice money, particularly money spent on travel going back and forth for visits. When they asked the staff how they felt about this in 2017, three quarters of them believed this would save travel time and enhance their job performance. And 81% believed that this would meet their needs as well as patient’s needs. It suggests that even before the COVID-19 outbreak, we are in a different moment now where telehealth is more affordable and more acceptable to people than it might have been a decade or two ago.

*“When we think about what makes an effective virtual visit, the ideal is to use both the audio and visual components.*
Helpful Tips

A couple of tips for effective telehealth visits involves monitoring your own behavior: How do I look? Am I engaged? What is my body language saying? A little bit of self-consciousness could work in our favor and make us more tuned in on what are we saying, not just verbally, but non-verbally.

We should think about boundaries when we think about the virtual visit. Having a sense of how much time we are going to spend, how that time will be spent, setting good expectations, getting the patients’ and caregivers’ consents for what you are going to discuss are all things to think about.

With telehealth, compared to a physician’s office visit, it is neutral ground that can have a humanizing effect. We see the patient in their own home, in their native setting where they belong. Additionally, you get many clues by seeing how they interact with their family. It gives the family or the caregivers a bigger role than they have if they come along to the physician’s office and it can have that leveling effect of putting everyone on the same page.

We do need to realize that a visit sometimes needs to be in person, but we should know why this is required. Is it because we need to do a physical exam that we cannot do through visual inspection? Home visits are always going to be necessary, but sometimes, we can do it just as well or even better through telehealth.

Michael Fratkin, MD

Michael Fratkin is Founder and Medical Director of Resolution Care Network.

I am Michael Fratkin, and I am a father and a husband and a bunch of other things as well as a palliative care provider living far, far in Northern California up in Humble County, about six hours north of the San Francisco Bay area. I built Resolution Care Network, a home-based palliative care program on the basis of burnout. I imagine that some of you understand the nature of having not enough resources to do what is there to be done in your communities.

I built a Resolution Care Network utilizing this principle that telemedicine is better than real life. The ways that I think it’s better than real life is that there are some practical concerns. The issues related to getting to my office, for a very seriously ill person and probably their daughter, taking time off from work, getting put together in the morning and dressed and showered and organized, and into the car with their walker, their wheelchair, or whatever devices. They have to drive maybe 10 minutes to a clinical environment – in my environment, three hours – to sit in a waiting room where there are 10-year-old People Magazines and the clipboard shoved in your face, again, for the fourth time in the last month. And you listen to that environment and notice the sounds and smells and differences of the people around you, and you have people coughing which has always been a struggle but now is certainly different, the risk and threat to the wellbeing and safety, to be put back into an exam room and, without windows with some diagram of the sinuses on the wall while you sit there twiddling your thumbs, waiting for the doctor to come in 20 minutes late and then to be interacting with you like this. Then reversing the whole thing to get home again, all in the interest of improving quality of life.

Those are practical considerations, but there are some more nuanced considerations that by creating a frame around a home visit that we can enter the space that a
person lives in, where they consider themselves the person they are, not the disease that they have. When we can enter that space and become present, without invading that space, we can become invited into their home and evaluate what their needs are, without intimidating. In that environment, on that level playing field, the ability to establish intimacy within the framework of this technological boundary, it’s actually much better than real life even though there are some real losses on the ability to put my arms around and hug a patient, the ability to walk into a room and scan the environment of their living room, to learn a lot of enriched intangible information. Those are things that can be worked around, but they are a real loss, as a home visit is a kind of unique environment. But there is a telemedicine visit, a virtual visit using video conferencing.

Nancy Fickert is a home-based Palliative Care Nurse Practitioner with the Lehigh Valley Health Network.

As a home-base nurse practitioner located in Allentown, Pennsylvania, I work on a base team with six other nurse practitioners, a social worker, two RNs, and a medical assistant. I am also supported by an inclusive hospital network with a shared electronic health record.

Prior to March 16, 2020, I was doing 100% face-to-face home visits. To help mitigate COVID-19 and to protect our personal protective equipment supply, our practice stopped all non-essential face-to-face visits. We adapted to virtual visits literally overnight using the telephonic and video visits. Our network’s administrative team adopted the electronic health record for us to include telephone and video visit templates so that we were capturing all required elements for billing.

You need to risk stratify patients based on acuity or level of risk, such as low, moderate, or high. And many things go into this: Their symptom burden, their stage of disease, their functional status, their access to resources, and what kind of family and caregiver support they have. This determines how often our patients need to be contacted by our team.

Virtual visits have to be easy for the patient and we had to find the right modality, and this takes a lot of consideration. For instance, does the patient have hearing loss? Do they have visual impairments? What kind of cognitive issues or language barriers might be present? When is the right time to conduct a virtual visit based on whether they need a caregiver to be present for support? Do they have the right access? Is there an internet connection? Do they have a smartphone? What other kind of technology might they currently have in the home?
The main barriers for us were connection issues. Some patients were just overwhelmed by the technology and they refused, they wanted their face-to-face visit.

What was critical to our success was that our clinical team was able to assist the families prior to visits with the technology and do a run through to make sure that they were able to connect. That decreased the frustration for everybody. There are times when we have connection issues and we convert those visits to audio.

I have been using telehealth for approximately six weeks and we have been able to grow our geographic coverage so that we can see more patients. My patient visits in a day have almost doubled and I feel more connected to my patients now than before. They are verbally telling me that they appreciate the more frequent follow up because they are not getting out to see their specialists right now, which means that managing their symptoms is more important than ever.

I am finding that I am being more aggressive with symptom management and am going to greater lengths to keep patients out of the hospital. In the past six weeks, I am having more direct goals of care conversations with patients and families about what might happen if they were to contract COVID-19, and we are being very aggressive at documenting these goals in a shared electronic health record.

In these conversations, it seems as if people are more willing to consider hospice because they fear going to the hospital and dying alone. Patients are watching the news about COVID-19 and anxiety is running very high, so having these virtual conversations and planning for the worst-case scenario seem to be welcomed. I am still present for patients and families to listen, provide that needed education and psychosocial support.

I have noticed there has been a decrease in ER visits and hospitalizations. The few patients that have landed in the emergency room or did contract COVID-19 are ones that were not able to participate in virtual visits.

Initially I was very skeptical about providing virtual visits, but after we kind of worked through all those technical issues, I really found it was an opportunity to have more focused visits with less distractions and obviously no travel time. I’m still prescribing, I’m still managing symptoms, I’m still completing post forms. I am accomplishing all the important aspects of a visit when the needed resources are identified, our support team is there to help with those needs.

I do believe there is still a need for essential face-to-face visit. I have to admit, I am looking forward to getting back out to see patients, but hopefully the reimbursement for virtual visits will continue because prior to this we did spend a lot of time doing telephone follow up that was not reimbursable. I am hopeful that maybe moving forward, this will be an avenue for us to stay more connected with our patients.
pressure cuff, so I can see in real time daily, their blood pressures. It prevents some of that potential for disease transmission and it has been very easy to get everybody to use this every day and not to share.

I also have eight public health and pre-PA interns from University of Maryland that have been indispensable in making outreach phone calls daily. Every time they call, these interns have been tracking COVID-19 symptoms, screening symptoms from the caregivers, assessing for possible caregiver burnout, giving advice and support for using the telehealth platforms, sharing information, and preventing isolation, of course. They have been essential for that human component.

I believe that I was able to master that pivot because as a PA we are trained as team players to work hand in glove, not only with our medical colleague doctors but also our colleague NPS, skilled nurses, home health agencies, hospice RNs, and geriatric care managers to just name a few.

Having this team approach is a key consideration for virtual visits. We can make life saving impacts whilst significantly easing the burden on the health systems that populations rely on. This is also an opportunity for PAs to join us altogether in answering the call as patients return home. Many PA have been extensively and rapidly cross trained and all necessary specialties and are ready to provide the continued palliative and advanced illness care from multiple sites using telemedicine.

We have proven that adding telephonic management of patients can lead to improve quality of life care outcomes and reduce cost to the health care system because we are helping keep patients out of the emergency room, the hospital and the ICU with this method of more ongoing care, and the focus of our tele-support nurses really is a continuation of what we do in the home.

One of the main things we do involves goals of care and advance care planning. It’s really important to make sure that we understand what the patient and family goals and wishes are and that we have clear documentation so that if something were to happen, we would have that identified and would know what the patient wants.

Other things we focus on with telephonic management are symptom management and medication management, which are key to helping patients stay safe and comfortable in the home. Necessary for all of this to work is building good rapport with your patient – patient engagement is one of those things that is key. If the patient is not engaged or you have not built a rapport, it is difficult to have any of this play a factor in what they are doing day to day in their homes.
COVID-19 Considerations

Regarding this current situation with COVID-19, I can offer a few considerations for the scope of the RN role.

One of the things to keep in mind is that the board of registered nursing requires that RNs be licensed in the state in which they are practicing. So, with telehealth, this may not be the state that they are working from or living in. For example, in our organization, we have a registered nurse who works from and lives in Utah, but our palliative care program manages patients in Northern California. In this case, the nurse had to attain additional licensure for the state of California. Some of these license restrictions have loosened due to COVID-19 but I would recommend checking with your local state board for that information.

Another consideration for the scope of the RN’s role involves diagnosing symptoms – that would be the role of the physician, the physician assistant, or the nurse practitioner. Yet, one of the things that we have found is that patients are often unable to get out of their house to get to their doctors, especially in this time of COVID-19, and they might be experiencing brand new symptoms, maybe even symptoms of an infection. The first provider they are reaching out to is the registered nurse through our telehealth program. We must be careful not to diagnose the symptoms, even though those symptoms might clearly be tied to something and it seems like there is a certain diagnosis that would fit. However, even without diagnosing symptoms, the RN is still effectively able to appropriately assess the patient and provide interventions and education to help manage the patient in collaboration with their primary care provider.

RN assessment is key to gathering enough information during a telehealth call. One of the things that we have learned is the importance of active listening skills for our staff, since in telehealth we are not physically there with the patient to assess them. We are relying on what the patient is telling us and what we can assess.

One of the things that we been working on for quite some time is incorporating video visits into our practice. With COVID-19, we have had to deploy these changes more rapidly. Both our nurses that do telehealth calls and our nurses that provide home visits have been given the technology through iPads to make a video visits with patients. The platforms that we are using are FaceTime, WebEx, or Signal.

For us, an important factor is how do you determine when to do a home visit versus a video or a telephone visit. There are a lot of different considerations that we work through when addressing what kind of visit to do for the patient. We risk stratify our patients based on their need. Our patients are often elderly with chronic illnesses, so you must consider if they have the capacity and the capability to be able to get onto these platforms.

Additionally, with COVID-19 there are some patients and some facilities that have some restrictions on visitors. We make visits to assisted living and boarding care and this has helped in that arena as well.

I think virtual care is just a wonderful way to continue to connect with patients and
provide support and help meet their needs.

**Support Team Tools**

We have created some tools for our tele-support team that we are sharing. The first tool goes over the structure of a routine telehealth call and guides the nurse all the way from opening the call, introducing themselves, getting the patient’s attention, letting them know what that visit is going to be about, and helping set those boundaries. The tool goes all the way to gathering assessment information and then providing appropriate interventions and disposition of the patient.

The second tool is a guide to triage calls since one of the things our program offers is a 24/7 triage line that the patients can call. When a patient calls into triage, the second tool goes over reporting urgent or emergent things outside of a routine call, how to address those types of calls, and what protocols to take.

The third last tool is called the clinical and technical scorecard. All calls are recorded and monitored to ensure that all technical pieces are addressed and that the patient received quality nursing care as a result of the phone visit. This is important for ongoing quality monitoring, both positive and negative, and areas of opportunity to help address the ongoing needs of our teams.

I'd give you a handshake or hug. Now, I want to acknowledge that this is very different for you and for us. My experience thus far has been that people really appreciate that and for those who are apprehensive or even defensive about this process, that it breaks a lot of that down.

There was an article in USA Today about Zoom fatigue for professionals. I think we must acknowledge that it exists for the patient and the people they love. I spoke to a gentlemen a couple of days ago and he talked about how many phone calls he is getting because every person is either calling or videoing him about his spouse.

So sometimes just acknowledge that.

As a social worker, I am a little bit different than the physician or the NP or the PA. In speaking with someone, I tell them, “I do not have an agenda and I know you’ve gotten a lot of calls, I’m sorry that it’s the case. I’m calling to see what you’re most worried about, what you’re feeling and how I can be helpful.” You must be prepared, as that can go a number of ways. Coordinating things with the folks that are in the hospital or if they are in the home and you have team members in the home, you have to coordinate closely and streamline messaging.

All of those in palliative care and hospice are aware of the mixed messages that people get. Right
now, people are especially sensitive to that because they are not at the bedside. We must make sure that we are doing our best to streamline messaging and whenever possible have some group meetings with those in the hospital and at home.

I had a recent call where one of my nurse practitioner colleagues was in the hospital and she had called me about the son of a patient who is elderly, has a lot of other issues, and now is COVID-19 positive and medically struggling. She was not able to help the son (who cannot be with his mother) get to the difficult conversations that were needed, although she is a very skilled clinician usually at doing that. So, I asked my nurse practitioner in the hospital if we could show him his mom first. Then can we talk together. We set up a Zoom call and it was, I would say, as rewarding as if we were there in person. At the end of the call, he made the important and difficult decision to focus on his mom’s comfort rather than medical care that is not helping her.

It can be helpful to think about or anticipate some of the issues that may come up in a call. For example, sometimes when I video or talk with folks, I am thinking that we are going to have a conversation about emotion or how things are going or advance care planning. But the family or significant other says, “You know what, I’m really frustrated because nobody has Face-timed me with my loved one.” I know that I am not going to get anywhere in my conversations with that person if we do not first address that issue. So being able to know your systems, know who’s present, and how to ramp those things up to get them resolved quickly earns you some trust, gets them the messaging that they need, and helps you move forward.

I think everybody is aware of what is happening in the areas of the country that have been bombarded so heavily by the COVID-19 crisis, like New York, for instance. Not only dying has changed, but grieving has changed, funerals and that process is very different. So, in social work a lot of people are bringing those things up, long before somebody dies – whether it’s themselves or somebody else.

It has been important for me to spend some time calling around to talk with some of the funeral directors in the area to get a sense of what issues are coming up. What are they dealing with, what are their practices, who can do a virtual funeral and who can’t, who is allowing people to go to a grave site and who is not? I will do this periodically because it is going to change, but this is important for our patients and the people they love.

One of the things that normally I do a lot but now find I am doing more often is help with scripting. I spoke to a gentleman the other day who needed help scripting for his wife, to talk to her about how sick she was and not knowing how to bring that up with her. I spend a lot of time around scripting for kids and adolescents, how to explain COVID and what is happening, how to explain why we are not going to the hospital, and not having a funeral.

All of these are things that your palliative care and hospice social workers have expertise in and can support the rest of the team with that process.

As social workers in this field, our client base is not just the patient and the people they love, but our passion is to also support the people with whom we work throughout our hospitals, our hospices. This crisis is causing trauma, psychological harm, and distress like nothing else that many of us have seen in our lifetime. One
of the things that we need to actively work on is finding ways to connect with each other and to support the people who are at the bedside, and in the buildings, or going into the homes. Some of us are spending more time doing our work from home, so things like Zoom drop-ins for nurses and other bedside folks are valuable. I have given my cell number out to colleagues if they need one-on-one time. Developing the list of the multitude of local and national resources that exists for health care providers on the frontline is as essential as everything that we are doing with the patient and their loved ones. If we do not develop these supports, if we do not watch out for each other, we are going to have even a bigger problem. My experience is that this has been really appreciated.

Judy Long, MA, MS

Judy Long is a Palliative Care Chaplain and Educator, UCSF Division of Palliative Medicine at University of California, San Francisco.

I am a chaplain in an outpatient palliative care clinic for a large teaching hospital in San Francisco. The populations I see, primarily, are patients with advanced cancers and patients with advanced neurological disease. For the last five years I have also been seeing people throughout the state of California, in Colorado, and Wyoming – a lot of people that may be very isolated.

The capacity to use telemedicine has been absolutely crucial, as a member of our team and certainly for me as a chaplain. A virtual consideration, and one that is an in-person consideration too, is the patient’s understanding of what is the chaplain’s role. As a chaplain, I would say people more often talk about coping strategies, about emotional balance, how to find resilience – spiritual resilience, or just human resilience – in the face of serious illness.

The patient’s possible connection to a faith tradition or faith community may inform not only the visit, it may inform treatment decisions, so the chaplain can gather that information, create a relationship, and share that with the team if they are not present.

I find that telemedicine is particularly wonderful because I can reach someone who is a caregiver for a patient, and the caregiver and the patient both may live on a ranch in Colorado. I have also used telemedicine to provide online live courses for caregivers who can talk with one another, so they benefit from that support and they can learn skills to help bring themselves some emotional resilience.

There are times when I go online with my team, so everybody is there. But there are definitely times when the patient or the caregiver may wish to speak with me or with one of the other team members individually. It is very important to assess for that need and to arrange that if required.

Additionally, I think it is helpful to let people know upfront at the beginning of a visit that it is possible that something may happen in the middle of the visit, like the call might be dropped. Let them know we will get back to them and how we will get back to them, so they are not totally taken by surprise and wondering what to do.

We can hold family meetings virtually and it is a wonderful gift to bring people together. There is the capacity to be present at a time when being there in-person is not an option. Here at UCF, we are in the midst of planning online memorials. There are people that cannot get out of their homes or gather together but they want to have some sort of a memorial, a caring way of recognizing the passing and the transition and loss of a loved one. They are doing that in community and that has been a beautiful thing to bring forward.

In thinking of bereavement and grief, there can be counseling and
support groups online, there are caregiver resilience groups that I provide for patients and caregivers. I also provide this for clinicians, and I would say that this has increased substantially since COVID. So, in addition to what I was already doing, which was teaching residents or primary palliative care to neurologists in different parts of the state or other states, now I am doing brief resilience trainings to caregivers in San Diego, which is five hours away from me. I mention that because it is a productive way that we can use telemedicine.

We can support our teams and the people that we work with. Our capacity to have team meetings and larger division meetings has grown immensely. And there is great humor, care, kindness, and variety in what we do together. One of our physicians said we need to do a flash-mob dance about how you wash your hands. And she led this thing and it was just fun. God gave people a chance to laugh right in the middle of everything that is happening.

I mentioned that as a fun aside but the fact is that we can use telemedicine in so many ways. I am very grateful that we have it.

Our patients are often in their mid-70s. A lot of people say age is a barrier in utilizing telehealth, but I would point you to a handful of 90-year-olds who are rocking it out on their tablets at home.

The biggest consideration regarding telehealth would be the platform. Our platform consists of a robust user-friendly platform where we have remote patient monitoring. We drop-ship to our patients a kit that includes a Bluetooth enabled blood pressure cuff, scale, pulse oximetry monitor depending on what they need, and very user-friendly education modules and surveys. Their medication list is also in the platform where they can monitor, and we can monitor – not only their vital signs but also their medication use.

There is an important piece that pharmacists pick up over video, and our social work colleagues pick up different elements, that all goes into my medication recommendations and vice versa for social work assessments. A lot of times it takes the team rounding every week to put all those pieces together for the best care plan. The COVID piece has been different for us as we have had to maintain trust with our patients. And that means making sure a team member is “showing up” and keeping our visit cadence going.

The face-to-face connection on video has been important. The self-efficacy of patients doing video visits is awesome. Remembering to praise them,
telling them that they are doing a great job, and forgetting that this is kind of a scary thing for them to be doing is helpful. My favorite part of doing telehealth is the look on their faces when they first sign on and they look surprised that you are there, and they are there, and you are online together.

The biggest thing I would say for our teams, especially during this time, is that you may be the only clinical person that they see that whole week. The more you can give permission to other members on your team to cross lines, cross boundaries, without crossing outside scope of practice the better. We use a transdisciplinary approach. So, all our disciplines are cross-trained. When I call, asking about how they are holding up, how their mood has been, as a pharmacist I am trying to cover as much as I can so that I can tee up my colleagues and their disciplines. And I always think, would I be surprised if they were hospitalized this next week? If so, then those patients get a quick check back by another team member to add another viewpoint. That is generally how we plan our cadence for visits.

Regarding medication management, this is a skill that everyone on our teams need to know. Targeted review and reconciliation are important. Some things I encourage would be getting beyond the list. When you are using video with your patients, have them take a minute and go get their meds. So, they are holding up bottles, showing you their pill box. The more you can say, show me don’t just tell me, is really important.

One thing that is applicable now is asking how they are getting their meds? Are they leaving the house and trying to physically go to the pharmacy? That is a risk factor. Is it possible to get them delivered? It is important to ask about Over The Counter (OTCs) medications. They might be getting prescriptions delivered, but they are walking down the street going into a retail store to get OTCs. We need to think, what can we do to minimize their risk of exposure?

We have found that this has been a useful time to address some deprescribing opportunities with our patients. For example, as they are getting close to running out of that third anti-hypertensive medicine that they are on, and their blood pressures are trending low, we have been working with their primary physician to let that go. We can say, why don’t we just do a trial, don’t even rewrite the prescription, we just try it and we will be monitoring them closely and set parameters to notify the physician. Physicians have been much more open to these deprescribing opportunities lately. I am calling this COVID lemonade. We are going to make lemonade out of this situation and try to get people off some of these meds that they do not need to be on.

We use active listening and open-ended questions to assess how people are coping with their situation. For example, I ask, “Tell me how you manage a bad day?” I like to keep that question open-ended because you never know what people might say. Sometimes it has to do with their mood and their emotion. “What do you do when it’s a rough day?” “What do you do when you have a lot of pain?”

Pay attention now, especially to those medication use behaviors because sometimes when people are at home alone with things that are dark and tough as they are right now, you can see coping mechanisms such as alcohol or other substances. We are paying attention to that as we are talking to our patients about their medications.
Quick Guide to Virtual Care

Here are some key points from NHPCO’s COVID-19 Quick Guide to Virtual Care.

By Steve Franey, Franey & Associates Consulting, Inc.
Steve Franey is an NHPCO Edge Partner with expertise in building and sustaining telehealth services.
During the COVID-19 Pandemic, short-term telehealth capacity is critically important and facilitates a rapid response. However, due to this unplanned transformation of the health care system, this technology may become part of the new “normal” in the long-term. Seek expediency while keeping an eye on creating a sustainable delivery solution that can be scaled once the national emergency has been lifted.

CMS recently provided flexibility during the COVID-19 pandemic to waive penalties for HIPAA violations against health care providers that serve patients in good faith through everyday communications technologies, such as audio-only telephone calls, FaceTime or Skype.

Providers should download the full Quick Guide to Virtual Care from the NHPCO website, additional guidance can be found in the appendices of this resource.

Telehealth capacity and utilization has never been more needed than now. The steps following are intended to help you and your organization better understand your telehealth needs as well as steps to consider in executing your telehealth plan.

**Planning** (Refer to this implementation checklist)

1. **Identify Telehealth Goal(s)**
   a. What do you want to accomplish with the introduction of a telehealth delivery capacity? (e.g., keep both staff and patients safe, improve efficiency, conserve personal protective equipment, provide greater patient access, reduce team burnout, etc.)
   b. Based on payment model, what disciplines on your staff would you like to utilize telehealth technology? Your response identifies service size/scope.
      i. Fee-for-Service
         1. Palliative Care (Medicare Part B - e.g., only physicians, physician and APRNs, etc)
         2. Hospice (Medicare A – face-to-face encounters and interdisciplinary team)
      ii. Value-Based—(e.g., physicians, APRNs, social workers, chaplains, etc.)?
   c. What type of service do you want to provide? (e.g., synchronous only, synchronous and virtual check-in, etc.)
   d. What segment of your patient population would you like to target with telehealth services?

2. **Designate an IT/Service Manager**
   a. Who on your team will manage the telehealth service? (e.g., coordinate platform selection and acquisition, develop telehealth policies and procedures, procure equipment and space, manage access, train staff, screen patients for telehealth capacity and appropriateness, collect and analyze data and patient/staff satisfaction, etc.)
   b. How will the designated manager be supported by internal or external technology expertise? (e.g., evaluate individual connectivity options, provide access orientation for patients/caregivers, solve video conferencing issues, etc.)

"...due to this unplanned transformation of the health care system, this technology may become part of the new “normal” in the long-term."
3. Screen the Target Population for Telehealth Capacity & Model Appropriateness

a. What percentage of the target population is interested and/or can be convinced to receive some of their care through telehealth?

b. What portion of the interested population is self-enabled or can be enabled through a caregiver/family member?

c. What questions will you need to ask patients to determine their capacity and appropriateness for receiving care through telehealth? Is the patient willing to have face-to-face visits using a video conferencing (telehealth) approach? Does the patient have an applicable video conferencing device (i.e., a front-facing camera on a mobile telephone, tablet, laptop or desktop computer)?

4. Determine Applicable Telehealth Payor Requirements

a. After Medicare, which payors, by percentage, insure the largest percentages of your target population?

b. Which payors reimburse for delivery of telehealth services?

c. How does each payor define telehealth, billable providers, necessary patient relationship, location of service, etc.? May these services be provided by Nurse Practitioners, Physician Assistants, and other Qualified Health care Providers (QHP)? How are telehealth visits to be billed?

Select a Technology Platform

1. Assess, Select and Acquire Telehealth Platform Access

a. Do you want to buy a turnkey solution or build your own platform?

b. Beyond video conferencing, what type of additional functions might you wish to integrate on the platform now or in the future? (e.g., peripheral devices [stethoscopes, blood pressure monitors, etc..], remote patient monitoring tools, translation services, etc.)

c. What are important platform selection criteria? (e.g., HIPAA compliance, minimum staff and patient hardware and connectivity, upload and download capabilities, ease of use for both staff and patients, integration into existing workflow and EHR, maintenance and upgrade expenses, upfront and monthly costs, etc.)

d. Who are some of the many vendor solutions to consider? Do you have an existing relationship? Can your EHR vendor integrate telehealth?

e. What hardware and connectivity will staff and patients need?

2. Acquire Necessary Staff & Patient Hardware and Connectivity

Implementation

1. Train Staff on Platform Use, Technical Problem Solving & Service Expectations (Use this etiquette checklist)

2. Obtain Patient Authorization for Telehealth Usage and a Waiver for Other Forms of Communication

a. What should be included in Telehealth Authorization Form that provides patient consent for this type of visit? (Download Guide from website and see Appendix A)

b. What should be included in a Communication Waiver if a patient is willing to use unsecured means of communication? (Download Guide from website and see Appendix A)

3. Schedule Patient Visit and Provide Initial Technology Orientation

a. What disciplines and individuals will need to be present for the visit?

b. Who will schedule the visit and where will it be documented?

c. Who will provide the initial technology orientation and instructions to the patient/caregiver and what will it contain? (Download Guide from website and see Appendix C)
d. How can no-shows be minimized, and access/technology problems solved?

4. Conduct & Document Visit

a. What amount of time should be allocated for different types of visits? (the amount of allocated time should include the face-to-face encounter, care coordination, and charting of visit and time spent)

b. How much time should be allocated between visits? (time for visit preparation should be built into each provider’s visit schedule)

5. Code and Bill for Visit

a. Face-to-Face Encounters
   i. For hospice face-to-face encounters: The face-to-face encounter completed through telehealth should be documented as such. Since it is an administrative function, the visit is not billable.
   ii. For medically necessary visits provided through telehealth during the hospice face-to-face encounter, the hospice should report the E/M code for the visit, using the 95 modifier. If the medically necessary visit is rendered by a nurse practitioner that has been elected as the hospice attending, add the GV modifier so that the Medicare Administrative Contractor (MAC) knows if the visit is to be paid at the ARNP rate (85% of the physician payment) rather than at the physician rate. The modifier 95 must be used for all telehealth services billed to Medicare.

b. Virtual Visits on the Hospice Claim Form
   i. Social worker phone calls can be added to the claim form for all phone calls to patients and families for social work services. Audio visual requirements do not apply, as this is a long-standing requirement for social work services.
   ii. No other disciplines in hospice may enter telehealth visits on the claim form at this time.

c. Documentation in the Electronic Medical Record (EMR)
   iii. Document all types of visits in the clinical record. If in-person visits were not made, document attempts and reasons for managing care through virtual visits.
   iv. Document the type of visit that will be completed to manage the patient care in the plan of care.
   v. The plan of care should reflect the plan for visits and how this plan is meeting the goals of care in a safe and appropriate manner

Download the full Quick Guide to Virtual Care from the NHPCO website.
360 Degree View of Grief and Bereavement Care in COVID-19 Pandemic Times

By Joelle Osterhaus, ACHP-SW, LICSW, MSW and Alissa Drescher, MA, LPC, FT, GC-C
MyNHPCO Bereavement Professional Community Steering Committee Members

Adapted from May 6 MyNHPCO Bereavement Professional Community Chat
A Violation of the Assumptive World

COVID-19 has had a huge impact on health care systems, including hospice. There have been a variety of responses and approaches, as communities are not all impacted in the same way. Service delivery has taken on many different shapes and iterations to reflect the needs of the communities that they’re in while taking into account the ever-developing research and recommendations that come from places like the CDC and state health authorities. There was a common reflection amongst all of us in the field that all deaths now seem to be COVID-19 related. And although hospice is well versed in loss and grief, this pandemic still uniquely affects our communities, our patients, our programs, and our staff.

One thing that we all have in common right now is a significant violation of the assumptive world, whether it’s personally because of a job loss or a sense of safety and security that’s no longer present. Maybe we don’t have access to resources as we did a couple of months ago, or our community has changed shape. Certainly, the families and patients that we serve through hospice are experiencing the same thing. Someone grieving a loss, and even our hospice professionals, are faced with daily challenges where our beliefs, assumptions, and meaning making constructs are being challenged. If we remember Maslow’s Hierarchy of Needs, many of us are feeling like we’re camped out in the physiological or safety realm, holding on for dear life and trying to figure out what’s coming next. This violation of the assumptive world will impact people for quite some time to come.

We know that when our sense of security in the world around us and how we can rely on those that typically might provide comfort, whether it be through rituals or just personal support after a death, changes shape, that violation may increase our susceptibility to a more complicated grief manifestation. We need to acknowledge that in some ways it is important that we take it slow and piece by piece because challenges for a lot of grieving individuals will likely come later on down the road. But it’s important to take a whole global view of how the patients, the families we support, their support systems, and our hospice teams are being impacted.

Impact on Patients

In this age of social distancing, patients are experiencing increased isolation from sheltering in place, which can impact and compound the anticipatory grief experience as patients reach the end of life. For instance, those hospice patients who would normally not be homebound are missing out on opportunities to fulfill final...
wishes like seeing the ocean, connecting with family members, or otherwise going out and interacting with others.

If the patient is COVID-19 positive, there are also increased feelings of guilt and shame, and some stigma attached to that. And in addition, there can be fear of spreading it to families and caregivers, or vice versa. Culturally, it’s very common that many patients do not want to burden the family members with having to attend or care for them; there’s a desire to be self-sufficient and autonomous. But now we have an additional layer of fear if they have a communicable disease.

And on top of this, the patient is still exploring and going through the journey of their own dying. And with that is a need and desire to connect with other people, but instead patients may be facing less autonomy or ability to make decisions. Patients may have less of an opportunity to determine who’s going to care for them. Perhaps certain family members are not able to travel to come and stay with them as they used to or might have planned to at another point. Or perhaps they had planned on going to a particular facility which is now closed because the facility has cases of COVID-19. The accumulation of these factors makes the grief experience more burdensome and challenging, and that has a ripple effect on others.

**Impact on Families Prior to Death**

There are some similarities in the experience of the family and the changes they are facing due to COVID-19. Many patients are in care facilities and separated from family members who are anxious and want to be with them as they approach their death. There is an additional burden on the family to have a sense that they are doing all they can in light of recent circumstances, and we know that’s something that our caretakers are always concerned about, but it is elevated here. On the whole, the idea of the good death than many family members have may just not be possible the way they envisioned it. Our goal in hospice, of course, is to create loving, compassionate care with an individualized approach. We want to honor the life of the individual patient and their family’s needs as best we can.

“There is an additional burden on the family to have a sense that they are doing all they can in light of recent circumstances..."
Other impacts can include decreased respite opportunities and decreased social support. Sometimes families have to balance risk of exposure to the virus with a sense of guilt that maybe they’re not providing what the patient needs, which can lead to increased anxiety, fear, and compounding anticipatory grief – including the fear of their loved one dying alone.

**Impact on Families After Death**

A lot of programs are seeing that family members are increasing the kind of access they’re seeking from bereavement services after a loved one’s death. The natural supports – friends, neighbors, spiritual communities – and formal supports are less available. When we’re reaching out via phone, we’re catching people more and they’re wanting to talk longer and receive additional follow-up calls. They’re also interested in online groups. Perhaps families are getting more tech savvy and comfortable with virtual support because that’s more of the world we’re living in.

While more people are open to virtual supports than we might have anticipated, and that has been helpful, there are still limitations that we need to acknowledge. Being with a grieving peer community in person is different. Not everyone finds virtual support meaningful, or they lack the technology and resources to access it, and some hospice programs do not have the tools to offer it. But that does not mean they’re getting left out; we’re need to make an effort to call and check in with those people more frequently. And there’s an opportunity for more community coordination, to connect with our program partners and other organizations in our areas to quickly connect the bereaved with resources.

Family members are also experiencing feelings of guilt, anger, blame, sadness, and depression; much of that is tied to secondary losses. If a person couldn’t see their loved one who died, or they were separated from loved ones due to travel restrictions, those situations can compound these feelings. Not being present for the death can contribute to delayed or ambiguous grief, a feeling of unfinished or unresolved business. As hospice providers, there’s an opportunity for us to visit with that caregiver down the road and fill in some of those gaps for them. That could be a rich and rewarding experience for them. Even if we weren’t the ones in the room, we might be able to get the details and paint a picture for the grieving family.

The COVID-19 related restrictions are also having a profound impact on funerals and other memorial rituals. The bereaved may be unable to see their loved one or spend time with the body, and funerals or cremations are limited or inaccessible. Some families have found success with virtual memorial services, parades of cars driving by the loved ones’ home, or planting memorial gardens. We’re finding that it really doesn’t matter how sophisticated or snazzy our events and our support are. It’s the simple and intentional things that people need. What we can do now is help families and the bereaved identify the unique, highly personalized rituals that they had with their loved one so they can continue that on.

**Impact on the Interdisciplinary Team**

Along with the impact that COVID-19 has on the dying and their loved ones, we need to acknowledge the impact it has on the hospice and palliative care interdisciplinary teams. It’s easy to focus on keeping things status quo and saying to ourselves, “We’re hospice and we deal with death and dying all the time.” But this is different, and the changes to our world have an impact on us, too.

Staff might have a difficult time expressing support without the use of touch as a healing and comforting piece of the bereavement process. That is a kind of secondary loss, both to the staff member and the bereaved, and it’s important to acknowledge and affirm that it’s a real part of their experience.

Many programs are also seeing increased staff ambivalence. This
might manifest in a wish to be at someone’s side while balancing the worry and risk of doing so. That risk includes potentially exposing the staff member’s family, too. There might also be differences in how different disciplines are experiencing this pandemic. Some may be wishing for more support from teammates, and others are thankful for extra cautiousness.

We’re also noticing increased staff grief, fatigue, and distress overall. As we witness the grief experiences compounded in our communities and within our patients and their families, we too are also experiencing grief at the loss of what things have been. That’s the undertone of this piece: we may be in this for a long time and there may not be a return to normal. We may see some changes that last for years, within either how we are operating, or how we design our programs and interact with one another.

**How are We Adapting and Coping?**

As we are adjusting to the changes in our day-to-day lives, teams are finding new ways to cope and help their coworkers as well as patients and families. There are some ways to make virtual support more effective and less stressful. For instance, plan for technical issues and acknowledge those right off the bat. Let people know it’s okay if these things happen, and if they get dropped off the call, we’ll call them right back. Make virtual eye contact with the person on the other side by lifting your eyes up to the camera. And end these visits just as you would in person with whatever your group ritual is, helping people find hope in between that session and the next one with you. Make sure they have the opportunity to tell us something that they’re looking forward to and feeling helpful about, as difficult as that may be in the midst of what they’re facing.

And it’s important for IDG teams to take care of each other. Some programs are hosting check-ins with the staff and doing meditation together. Music therapists are offering live streamed visits that the IDG can participate in. Teams are having virtual coffee breaks or happy hours, and even doing parking lot roundups. The best thing people can do as a team is support each other with self-care.

While the effect of COVID-19 is great, hospice organizations are in a unique position to positively impact those we serve. We are ready to face these changes! This is what we do. We are a community, so rely on one another, and reach out to other hospice and palliative care professionals if you need to. You are not alone.

We are a community, so rely on one another, and reach out to other hospice and palliative care professionals if you need to.
LOOK NO FURTHER... The annual State Hospice Profile™ contains comprehensive hospice market characteristics for each county based on Medicare data from 2004-2018, providing critical information to learn more about the competitive environment of your state.

Produced by HealthPivots and available exclusively through NHPCO Marketplace, each year’s State Hospice Profile™ provides vital county level information on each of the leading providers. Full-colored charts and graphs provide analysis information of the last fifteen years of Medicare claims data.

Examples of the valuable information included in the State Hospice Profile™
- Estimated Medicare Cap usage
- Major hospice providers in the county
- Comparative hospice penetration data/market share trends
- Average Length of Stay
- Distribution of hospice census

As an added bonus, each State Hospice Profile™ also contains a National and Statewide Profile of hospice care based upon Medicare claims data going back to 2004, as well as county level National and State penetration maps. View an example of a State Hospice Profile™ at https://healthpivots.com/wp-content/uploads/2019/10/palm-beach-county-sample-atlas-2018-page.pdf

State Hospice Profiles™ are individually priced based upon the number of counties in each state. Please call 1-800-646-6460 for pricing details and to order. Profiles are available for all 50 States, the District of Columbia, and Puerto Rico.
A Social Media Campaign

Unity Hospice sharing a brave face during this crisis.

#hapcFacesOfCaring
Social media...

has become a place of refuge for many during the COVID-19 pandemic. While scrolling through Instagram, Twitter, and Facebook feeds, it’s commonplace now to come across photos or news stories of frontline health care workers in the line of duty, donning PPE, and caring for those stricken with illness. NHPCO wanted to create a space on social media for hospice and palliative care teams to share their photos and stories about caring for patients and families during this health care crisis.

Programs have had to adapt their care delivery while using creative and meaningful ways to meet the needs of their patients. #hapcFacesOfCaring allows them to share their face and voice with the world as they care for the most vulnerable population during this unprecedented and challenging time.

The photos and stories NHPCO has received show some of the best parts of humanity. Many are pictures of the interdisciplinary team members wearing masks and conducting daily work like team meetings virtually or minding proper social distancing measures while preparing to care for patients.

Those who are working in facilities are doing their best to keep their patients’ spirits lifted. Rhonda, an AseraCare patient, wanted to celebrate her birthday with her husband. With the help of the Dreamweaver Foundation and AseraCare, Rhonda was gifted balloons, flowers, and dinner, and was able to spend time with her husband, even if it was behind glass.

Hospice volunteers are also feeling the impact from COVID-19 and the change in visitation rules. But that hasn’t stopped them from finding ways to reach and care for their patients and their hospice teams.

Johnny Simmons, Heartland Hospice veteran volunteer, had been visiting with patient Robert since February. They hit it off right away when Robert invited Heartland into his “barracks.” Johnny visited Robert every other week and they always had good talks about their time in the military. Johnny brought some of his military equipment during one of their visits, which sparked a lot of conversation.

Due to the visitation restrictions from COVID-19, Johnny was only

The photos and stories NHPCO has received show some of the best parts of humanity.
able to visit a couple of times but made numerous attempts to reach out to Robert via phone calls. Robert began to decline quickly. A Heartland Hospice social worker arranged for Johnny to see Robert one last time, even if it was from the other side of the window. Johnny said goodbye and took a step back to salute Robert, a friend, brother, and Hero.

There have been many photos of pet and music therapy happening on the other side of a window. Music therapists are getting creative and recording songs for their patients to listen to since they can’t physically be by their side. Some hospice teams and volunteers have held impromptu concerts outside patient windows to provide comfort and joy.

Volunteers are bringing their furry volunteers to greet patients from outside to let them know they are still here and thinking of them even though they can’t make their in-person visits. And not surprisingly, there are no shortage of photos of the canine persuasion doing what they do best, making patients smile, even if it’s from a distance!

NHPCO thanks all the hospice and palliative care providers who have participated in the campaign. We are inspired by your creativity and dedication!

To see more pictures on social media, search #hapcFacesOfCaring. NHPCO is still accepting submissions online at nhpco.org/Faces-Of-Caring.
We connect you with qualified hospice and palliative care professionals.

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There are several pricing options available and NHPCO members receive a discount.

Learn more by visiting careers.nhpco.org/employers/
The first book to validate the meaningful dreams and visions that bring comfort as death nears, Death is but a Dream, has been written by hospice physician Christopher Kerr, MD, PhD. NHPCO is pleased to share an excerpt from Death is but a Dream, with permission of the publisher Avery, a member of Penguin Group (USA) LLC, A Penguin Random House Company. Copyright © 2020, William Hudson, LLC.

NHPCO is proud to have Dr. Kerr serve as one of our keynote speakers for the 2020 Virtual Conference (July 22 – 23) and as a keynote for the Virtual Interdisciplinary Conference that begins October 12, 2020.
For some patients, the peace and understanding gained at end of life is achieved through dreams and visions that wash over them, summoning up images and emotions that soothe and appease. Others attain perspective through a more conscious process of reflection that they methodically apply to their end of life dreams and visions. These are patients who are keen on trying to understand the mysterious process through which death is somehow turned into a familiar, even welcome friend at life’s end. This was true of Patricia, for instance, who had been so eager to help us move our research along. The conclusions we reached through the study were truly remarkable, but it took patients like her to give them a human face. Patricia had such an exceptional recall of her end of life dreams and visions that she became one of our richest points of access to the comforts provided by these experiences.

When she arrived, Patricia took Hospice Buffalo by storm. She was ninety years old, and nothing about her past, physical condition, or appearance could have prepared us for the engaged, alert, and witty person she revealed herself to be. She had advanced pulmonary fibrosis and often struggled to breathe at rest despite being permanently connected to a portable oxy-gen tank. Patricia’s condition was so advanced that she could not walk across the room without experiencing severe respiratory distress, but she made up in verbal delivery what her body couldn’t deliver in mobility. She spoke in as uninterrupted and fast a flow as an auctioneer. Talking to her for any length of time inevitably eclipsed her physical symptoms or the medical equipment she depended on, so much so that someone once remarked that she wore her nose tube like an accessory. She was so self-possessed that anything connected to her body, artificial or otherwise, looked like an extension of her, no different from the horn-rim glasses or the butterfly hairpins she wore. She was also intellectually vibrant and curious, and we found ourselves thinking of her more as an interlocutor than as a patient. Patricia maintained a desire to engage and express herself right up to the very end, even when her disease had progressed to the point where she longed to die.

Her mother had died of pneumonia when Patricia was nine, and at thirteen, she’d begun taking care of her father, who had been diagnosed with the same disease Patricia now had, pulmonary fibrosis. They did not have access to the social services that are now available to severely ill patients and their families, so caring for him was a full-time job. Patricia’s description of this period in her life revealed how, in the post-depression era, maturity at an early age was not the luxury it became for later generations of American teenagers: “I had to be a caretaker from the time I was very, very young. It was a difficult role to play at any stage but particularly difficult when you are thirteen. I never resented it, though, not until I came to these crazy dreams.”

Patricia’s “crazy dreams,” as she put it, fascinated her. She wrote extensively about them in her...
diary and happily shared her abundant commentary with us. She was grateful to be around people who not only took them seriously but with whom she could discuss their singular nature. "It isn't the morphine, then?" she asked when we first broached the topic, relieved to know that experiences that mattered to her were not just drug-induced hallucinations. And after pleading with me not to su¬garcoat what was happening to her, she added, "So there is a pattern to this thing? Being bossy and inquisitive, I am going to ask you a hard question: Is there any way of knowing where on this graph I am?" She had realized that there was a connection between dream frequency on the one hand and one's closeness to the end on the other, so there was no stopping her analytical mind from trying to identify a logic to the changing patterns of her dreams. Accustomed to managing lives from a young age, she was now working on managing her last moments, including anticipating her time of death.

As her condition worsened, she increasingly spoke of death as deliverance, so much and so often that her grown children became uncomfortable, asking her to refrain from mentioning it in their presence. I could not blame them. Here was the mother they cherished, who was talking about her death, which was also their loss, as something to scratch off her to do list. It felt to them like she was discussing her pre-death dreams as if she were conducting a laboratory experiment.

I knew better than to mistake this obsession with death and dying for cheap morbidity. Patricia had spent her life taking care of others. She had tended to her dying father at an age when most kids are preoccupied with fantasies about running away or stealing a smoke; she had lived through the war, the rationing system, the anxiety of not knowing whether her fiancé would survive his armed service to the country; and she had raised kids in a household where she'd had to "wear the pants." Having spent a lifetime managing others, she was now preparing for her own exit, as much for her sake as for theirs. After all, only the unexpected can be traumatizing, so preparing herself for death was one way of averting trauma, for herself as well as for her loved ones. Patricia had spent her life worrying about them, and she was not about to suddenly change course at its end. If anything, people's character traits get more pronounced with age. The following passage that she once read to me from her diary illustrates this best: "I am of no use to anyone now, I hate to think that. I have to get help with stuff and it will only get worse, I am sure. So that is why I am saying let's get on with it. I dearly love all the ones that are still here, but I can't do anything for any of them, and it is too bad that they have to bother about me. So this morning, I'd like to cry but I don't. I'd like to have my mother tell me it is ok. I'd like to wake up and walk up to Chuck [her husband] and take him by the hand and walk into the eternal sunset, but that is another story, another breath, another day."

Patricia was alternating between fear of the unknown and a sense of defeat, disguising both under a veneer of casualness she did not truly feel. It was a facade meant to reassure herself as well as others. After all, she was not one to draw attention to her troubles. "Everyone has problems," she would say. "I would never go down the hall and complain, because there is always someone worse off than I am."

Certainly, there were extreme episodes of breathlessness that would coincide with her feeling utterly dejected and pleading for a swift death, but until the last week of life, these pleas were more cries of exasperation than of conviction. On her deathbed, several days before the end, she admitted as much: "You try your darndest to get better because so many people depend on you, but now I am content to just leave everything. That started just recently." This was also when she somehow found the strength to remember and recite Hamlet’s famous soliloquy: “To die, to sleep. To sleep, perchance to dream—ay, there's the rub. For in that sleep of death what dreams may come.”
Patricia had a way of making me do homework I should have attended to in college; I once again had to resort to Google to brush up on what it was that concerned Hamlet about the after-life. I did so later that day and smiled, remembering how several weeks earlier, she had apologized for inadvertently interrupting me when I was handing out instructions to staff: “You’d better watch out or I’ll be sitting in your seat soon,” she said. I was going to miss her.

For Shakespeare’s forlorn hero, the fact that we don’t know what lies beyond “when we have shuffled off this mortal coil” is what makes us stretch out our suffering for so long. I suspect that what kept Patricia hanging on to life for as long as she did despite mounting pain and her exhortations to the contrary had everything to do with love: of family and of her research team at Hospice Buffalo. I am also grateful that her end of life experiences helped bring her, one of the most selfless human beings I knew, back in touch with her core self.

On one of my last visits with Patricia I asked her, “Who would you want to see in your dreams going forward?” even though I already knew the answer. As predicted, she replied, “I’d like to see my mother because I never got to know her.”

I went to see Patricia one last time before she died. She could no longer speak and looked unresponsive. I bent over and asked her in a whisper if she’d seen her mother, not truly expecting an answer. She smiled, nodded, and pointed upward.

Nothing was said and everything was understood.

Patricia was alternating between fear of the unknown and a sense of defeat, disguising both under a veneer of casualness she did not truly feel.
Music Inspired by the Compassion and Hope of Hospice is Recorded by Nashville Artists

Proceeds from The World Around the Bed: Songs of hope and healing will support PPE supplies for hospice providers

The birth of the Hospice Music Project began in November 2018 as part of NHPCO’s Interdisciplinary Team Conference in New Orleans. At a conference session led by hospice physician and musician John Mulder and GRAMMY award winning songwriter Tricia Walker, hospice professionals shared reflections of their work. They put words to the many emotions experienced in caring for people often near the end of life. Walker and Mulder shaped those words and wrote the music to create the first recorded song, Joy in a Teardrop. The Hospice Music Project was born.

NHPCO, along with John Mulder and Tricia Walker are proud to release the new recording, The World Around the Bed: Songs of hope and healing. Featuring 11 original songs created from the experience of hospice heroes from across the country, The World Around the Bed... reflects the joys, sorrows, difficult and challenging times, and even the lighthearted and humorous moments that are a part of life’s journey.

“These gifted and compassionate hospice professionals lovingly shared their thoughts, ideas, and stories with us and then allowed us to shape their ideas into the special songs that have been recorded for this unique project,” said co-creator Ms. Walker. “These songs really do express the hope and healing that hospice professionals provide each and every day.”

“We feel that this will be one more effective way of communicating the sacredness of our work and establishing a testament of our wonderful legacy,” added co-creator Dr. Mulder.

“During the challenging times our country, indeed the world, is facing as a result of the COVID-19 pandemic, songs that emphasize love, compassion, and hope are needed now more than ever,” said NHPCO President and CEO Edo Banach. “Now, the proceeds from the sale of The World Around the Bed... will help bring much needed personal protective equipment (PPE) to providers in the hospice community, many of whom are struggling with lack of supplies, putting their own safety at risk.”

The album may be purchased through the NHPCO Marketplace online or by calling NHPCO at 800-646-6460. The World Around the Bed: Songs of hope and healing is also available on Amazon Music or iTunes.
America is facing a shortage of available personal protective equipment (PPE), and many pieces of PPE have gone up in price as demand has increased. Hospice and palliative care providers are facing increased challenges to acquire and pay for this critical equipment needed to care for vulnerable patients and families while also protecting their workforce. To mitigate these challenges, the National Hospice and Palliative Care Organization’s fundraising affiliate, the National Hospice Foundation, is providing grants to hospices in need for purchasing PPE through its Workforce Emergency Support Fund.

As of May 27, 12 hospices that have incurred a significant financial hardship from the coronavirus pandemic or are in coronavirus hot spot locations have been provided grants up to $2,500 to purchase PPE. This funding was made available in partnership with the Cambia Health Foundation and other generous donors. To date, more than $55,000 has been donated to NHF to support this important initiative.

“We're proud to be able to offer these grants for PPE. Our members provide critically important care in their communities, and they need the proper equipment to keep their staff and their patients safe. The PPE grants are part of our ongoing efforts to address our providers’ needs during this public health crisis,” said Edo Banach, President and CEO of NHPCO and NHF.

All current NHPCO provider members are eligible to apply for a PPE grant.

For those interested in supporting the supply of PPE for hospice professionals, direct donations may be made to NHPCO’s affiliate the National Hospice Foundation (please designate the Workforce Emergency Support Fund on the online donation form). So far, NHF’s Workforce Emergency Support Fund has collected more than $55,000 that is being distributed to hospices in need of protective equipment.

The PPE grants are part of our ongoing efforts to address our providers’ needs during this public health crisis...
2020 Interdisciplinary Conference Goes Virtual

Innovation and participant flexibility will be hallmark of new event

Due to the ongoing COVID-19 pandemic, NHPCO decided that the in-person 2020 Interdisciplinary Conference (IDC) that was scheduled for October 12-14 in Little Rock, Arkansas will not be held as originally designed. NHPCO will instead deliver a Virtual Interdisciplinary Conference that will take place over a three-week period, October 12-30, 2020.

“While we look forward to a time when we can reconvene the hospice and palliative care community face-to-face, the NHPCO staff is exercising its creativity and imagination to deliver a virtual event different from anything we have done before,” said NHPCO President and CEO Edo Banach.

The Virtual Interdisciplinary Conference will take place over the span of three weeks, with the same high-quality content and opportunities to engage that were planned for Little Rock. The conference will include live programming and on-demand content. There will be more than 60 hours of content, falling within seven learning tracks, as well as opportunities for participants to network and connect with colleagues from across the country and NHPCO staff. Additional downloadable resources that can be viewed off-line will also be available.

The Virtual Interdisciplinary Conference will include a virtual exhibit hall that will allow participants to meet and connect with a wide variety of vendors and service providers.

For individuals or organizations who had already registered to attend or exhibit at the face-to-face IDC that was set for Little Rock, they will be receiving a separate, detailed communication about options to participate in the Virtual Interdisciplinary Conference.

Information about the Virtual Interdisciplinary Conference, including helpful FAQs, is available online. Registration is open now!
NHPCO’s annual webinar series provides you and your team with the education to help you do your job best. With topics and speakers carefully curated by NHPCO Committees and Councils and feedback from you. Save even more with a package. Register now and complete your 2020 education calendar.

2020 Webinar Series

JANUARY 9  Self-Care and Resiliency
JANUARY 28  Developing Individuals to Cultivate Team Health
FEBRUARY 13  Reimbursement Issues in CBPC
FEBRUARY 25  Documenting and Defending GIP Status
MARCH 12  Design Thinking for QAPI - Give Your QAPI Program a Jumpstart
MARCH 31  Optimizing Medical Treatment at the End of Life
APRIL 9  Screening and Assessing for Spiritual Suffering: What All Staff Can Do
APRIL 28  Facilitating a Healthy Work-Life Balance
MAY 14  Strategies for Engaging Referral Sources
MAY 26  Implementing the Hospice Election Statement Addendum
JUNE 11  Benchmarking for Cost and Quality
JUNE 23  Advances in Wound Care
JULY 9  Caring for Difficult Patients and Families
JULY 28  Effective Team Meetings
AUGUST 13  Medication Management Expectations in Consultation vs. Co-management Arrangements
AUGUST 25  Hot Topics in Quality & Regulatory
SEPTEMBER 10  Disaster Preparedness: Measuring Up
SEPTEMBER 22  Pain Management for Patients with Addictions
OCTOBER 8  Responding to Challenging Psychosocial Needs
OCTOBER 27  Supporting Patient/Family Choices: Honoring Their Values
NOVEMBER 12  Partnerships Across the Care Continuum
NOVEMBER 19  Revocations, Live Discharges and Transfers
DECEMBER 10  Dashboards and Metrics to Communicate Outcomes
DECEMBER 17  Evidence-based Symptom Management for Agitation and Restlessness
Given the demands on our time, budget constraints, and the challenge of finding work-life balance, there has never been a greater need for on-demand, online professional education. NHPCO is proud to share our upgraded On-Demand Education website.

**Enhanced User Experience**

The On-Demand Education website has been redesigned and built for a better online learning experience. The up-to-date design features a clearer navigation structure and search functionality that will help all professionals interested in person-centered care find a course that matches their specific learning objectives. Visitors will find easier site interaction with fewer clicks to access course content and complete education activities. The re-imagined On-Demand Education website is responsive, so courses can be accessed via any digital device, with no usability concerns regardless if a user is accessing a course via PC, laptop, mobile, or tablet.

**Curated Course Catalog**

NHPCO's staff, faculty, and members of the Professional Education Committee have gone through all available courses on the previous E-OL site to select only the best topics on relevant areas of practice and timely topics that bring value to hospice and palliative care professionals. With a collection of courses that are available 24/7, users can stop a course and resume later, making learning available to the user when and where they are ready.

**Instructor-led Courses**

NHPCO also features a series of live, instructor-led courses that begin throughout the year. Part of our Manager Development Program, popular instructor-led modules that are coming up include:

- *The Interdisciplinary Team: Key Skills for Hospice Managers* beginning July 27
- *Managing Conflict in the Workplace* beginning August 3
- *Ethics for Hospice Managers* beginning August 24
- *Managing the Changing Organization* beginning September 14

Registration for the upcoming live modules is open now and these courses tend to reach capacity quickly.

**No Additional Cost for CE/CME**

CE/CME is available to member and non-member course participants at no additional cost. Users have the flexibility to select and claim CE/CME credit and certificate of completion from within the learning portal. Our upgraded site will allow users to determine the number of CE’s completed at any point during the year or at the end of the year for an easily accessible summary.

**Reduced Pricing Structure**

To encourage professionals to take advantage of this valuable digital learning portal, NHPCO is announcing a newly revised pricing structure: 30 to 50 percent off ALL courses (except for the Instructor-led MDP Modules). Additionally, various course bundles are now available in a variety of topics at a discounted rates.

**NHPCO Commitment**

As part of NHPCO’s strategic priorities for 2020-2021, the organization is committed to making high-quality professional education available in a range of affordable formats that will address the skills and training needed to not only survive but thrive in today’s professional world. Ongoing upgrades to improve our On-Demand Education website will include video,
enhanced media, and interactive features that will increase engagement and enhance the learning experience. Educational programming will expand as more on-demand courses are added and instructor-led sessions are offered.

Visit NHPCO’s On-Demand Education website and take advantage of the redesigned learning portal created for hospice and palliative care professionals and others interested in interdisciplinary care.

To contact the NHPCO education team, please email education@nhpco.org – they will be happy to assist members and non-members interested in On-Demand Education or other NHPCO professional development opportunities, such as conferences and webinars. Visit the education page at nhpco.org/education to learn more about the range of educational programs that are available.

Educational programming will expand as more on-demand courses are added and instructor-led sessions are offered.

Your Palliative Care Needs

It is time to participate in the 2020 NHPCO Palliative Care Needs Survey! The 2018 survey resulted in publication of a national report that informed policy and advocacy efforts; requesting a Community-Based Palliative Care model; development of the NHPCO Palliative Care Playbook; and education resources. Your voice matters. Primary member contacts will receive a link to the survey in late June, when it arrives, please take 15 minutes to complete the survey to help us help you.

Pediatric E-Journal: Ethical Issues

The 59th issue of the Pediatric E-Journal is available online. This issue is focused on ethical issues in pediatric palliative and end-of-life care. Ethics is defined in its simplest form as a system of moral principles. Questions of justice, distributive justice, autonomy, beneficence, nonmaleficence, and truth telling have been highlighted repeatedly recently, especially in the media. At an organizational level, and especially in hospice and palliative care, these principles are at the heart of everything we do, not just during a pandemic.
We Honor Veterans Program Unveils Redesigned Website and Logo

We Honor Veterans, a program of NHPCO in collaboration with the Department of Veterans Affairs, launched a refreshed website and logo in April. Visitors can access the website at the same URL, wehonorveterans.org, where they can find resources for serving Veterans, information about VA benefits, and more. Organizations that participate in the We Honor Veterans partner program can also use the new website to access partner-specific resources and logos.

The new website provides better access to information that can help hospice and palliative care providers serve and honor the Veterans in their care and their community, and to better celebrate and share the work these providers are doing.

WHV partners are encouraged to visit the new website and keep an eye on the blog and event calendar...
New features include an updated partner portal, resource library, blog, redesigned partner directory, new event calendar, and an updated homepage with quicker access to essential content. WHV partners are encouraged to visit the new website and keep an eye on the blog and event calendar for the latest updates.

To help partners navigate the new layout of the website, WHV created two tutorial videos. The first reviews how to access partner resources, the partner directory, submitting a story, and adding events to the WHV calendar. The second tutorial video demonstrates how to log in to the website, view the partner portal, access level-specific logos and certificates, and submit an activity report.

Along with the new website, We Honor Veterans unveiled a new logo. This logo mirrors the NHPCO branding, reinforcing that We Honor Veterans is a member of the NHPCO family while maintaining a focus on serving Veterans.

New partner logos are also available to match the new program logo.

The new website provides better access to information that can help hospice and palliative care providers serve and honor the Veterans in their care...