

It does not matter if you have been doing hospice work for a few months or many years. Changes are always happening around us. These changes affect how we provide care. Change often brings on the “I remember when...” stories. Some may wish for the “Good Ol’ Days” while others enjoy the structure we have now. As hospice continues to grow and evolve, we can provide care in a different more efficient way.

How do you measure the success of the care that you and your team is delivering? Prior to the Pandemic? During the pandemic? And how will you measure that success after the pandemic? Caseloads are higher, expectations of numbers of visits are higher. Do more with less. Is this a new theory? No, we have been talking about this for years. Yet, more than ever right now we feel a lack of control. Prior to the pandemic, we placed this lack of control on decreased staff, sicker patients at end of life, and mini-intensive care units in the home setting. During the pandemic, we blame the pandemic. What will we blame after the pandemic?

Perhaps instead of feeling that lack of control we look at how we measure success? During this time, you may be feeling isolated and missing your fellow IDT members (including team leaders). We are, after all, the story tellers, story listeners and only we understand the stories. Hospice stories are not stories that we share with our families at the end of the day, they do not want to hear about that death and dying stuff. If we can’t tell our stores and hear our peers tell us what a wonderful job we did in such a difficult situation how are we measuring our success?

When you do hospice work you give all, all of the time. By telling our stories and having those stories validated we get filled again, we share a comradery that others don’t understand. We are huggers and touchers. We want to hold the hands of those patients who are dying, we want to sit by the bedside. We want the time to do that and now during the pandemic not only are we not graced with the time, we simply cannot do the things that we have traditionally used to measure our success.

Decreased in-person visits, social distancing, telehealth visits, delivering end of life care behind a mask and a shield these are the tangible changes that present challenges to providing hospice care in our usual fashion.

Measures of success in this sea of change is the ability to adapt- increasing phone contact, optimizing the in-person visits with video buddies from other disciplines, including facilitating communication and contact with the patients’ families if they are apart. These adaptations are not a measure of the success of the individual changes. The success is instead the adherence to the true north that is the vision and goal of providing compassionate, palliative end of life care, though it may look different.

If you provide hospice care, you may have experienced a trauma in your hospice journey. Homeless patients, patients dying alone, pediatric patients, veterans with Moral Injuries and re-living their horrors from combat as they take their last breath. The patients and families we are caring for are experiencing their own traumas right now as well. Families separated from their loved ones in facilities that they are unable to enter, saying their goodbyes on the phone or some meeting room on a handheld device. The pandemic is making it extremely clear that we are facing, potentially, more direct and indirect trauma in our jobs.

Did you think you would ever equate hospice care with telehealth visits or window visits? How do we measure the success in that? What refills and refuels you for another day? How do you assure that moral distress, compassion fatigue are minimal as you do your job?

Do you depend on the leadership of your organization to understand the duties you perform every day? Do you look to them for the refuel and refill? Are they trauma informed in how to help you survive your job? How is success measured?

Perhaps, just perhaps, we need to redefine how we personally measure success at the end of our workday. Did you help a family connect by a phone or a handheld device? Did you call a family, unable to see their loved one in a facility after you did that window visit and describe to them what you saw? Did you go the home of a caregiver and sit, socially distanced, from them and hear their distress and did you provide comfort to them? You should measure these things as a huge success. Without you, that family member whose loved one is not accessible to them would not know what is happening to the patient. You have assured them of the comfort they want to hear about.

Did you bathe a patient and call the family to let them know that the patient smiled as you hummed while you worked? HUGE success again.

Did you go home at the end of the day and care for yourself? Now add that you did not feel guilty for this. Did you reach out on the phone to a co-worker to describe your day? Cry and laugh with them. These are our success stories to tell and forever hold on to.

Now is the time to redefine how we measure success going forward. When we get through this pandemic, we can know that even with higher caseloads and more visits in a day we are doing something that no one else can, we are delivering the best end of life care that we can. By not wishing for the “Good Ol’ Days” and looking at hospice as it has grown, we set new expectations for measuring the success in the care we provide.

Resources and Tools:

<https://www.nhpc.org/education/tools-and-resources/trauma-informed-end-of-life-care/>

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This resource was developed by the NHPCO Trauma Informed EOL Care Work Group, April 2021.