

Dr. Ira Byock makes an ethical and business case for investing in palliative care

November 1, 2021

Practitioners strive to preserve the dignity and 'fullness of life' for patients facing chronic illness or death

By [JULIE MINDA](#)

The role of palliative care practitioners is to relieve the pain and suffering of people with serious illness and to improve their quality of life. Dr. Ira Byock says there has been a great and pressing need for such care throughout the pandemic.

Byock is a leading palliative care physician and founder and chief medical officer of the Institute for Human Caring at Providence St. Joseph Health. That institute aims to promote whole-person care, which it defines as care that is aligned with patients' goals and based in relationships, and that recognizes each patient's physical, emotional, social and spiritual needs.

Byock, who has authored or co-authored five books on palliative and end-of-life care, spoke with Catholic Health World about how palliative care is demonstrating its mettle during the pandemic.

The conversation has been lightly edited for length.

What has the pandemic taught the U.S. about palliative care?

Never in the history of palliative care has the value of this skillset been highlighted as it has during the pandemic. The importance of examining our mortality has become paramount and it's become clear that all of health care occurs against the backdrop of human mortality.

What are the main challenges of providing palliative care in a pandemic?

The main difficulty is that there are not enough palliative care providers to go around. The teams are incredibly strained and stretched, and they are showing obvious signs of wear and tear. A year ago, our palliative care teams were running on fumes and were exhausted emotionally and physically. By late 2020, the fumes were gone, and they were dragging themselves to work, and we were really worried by spring. Then we had a break as vaccination spread and outbreaks went down. Palliative care providers were taking vacations and turning to focus on self-care.

But then the delta surge hit, and we're again legitimately worried about their health and emotional well-being.

Has palliative care staffing been adequate, given demand?

It is important that we acknowledge that the pandemic showed us that there is a shortage of palliative care practitioners, including in Catholic health care. One can hardly exaggerate how stretched our clinical teams are, including our palliative care teams.





This poster from Providence St. Joseph Health's Institute for Human Caring can be affixed to a wall in a patient room. It prompts caregivers to get to know their patients as individuals. It's also available in Spanish.

There has been, in the past, a tolerance for maintaining threadbare palliative care programs. For instance, there are so many palliative care programs that are just available during weekdays or are closed on holidays. Suffering does not take a holiday. Now, with the pandemic, those deficiencies are very hard to ignore.

Within Providence, we've been calling attention to the need to expand palliative care staffing for a long time. Our data showed that there were significant numbers of patients with unmet needs for palliative care. Because of the pandemic, the consequences of not having expanded staffing are more obvious to all.

How are you making the case for increasing the number of palliative care practitioners?

We at the Institute for Human Caring and at our Palliative Practice Group have used this crisis to measure the impact of palliative care. We have shown how it improves the quality of the patient experience and is cost effective in terms of measures like bed use.

Can we improve quality while also diminishing the use of highly burdensome and nonbeneficial care? If so, this is another aspect of a business case for expanding palliative care resources. It's worth looking at the best clinical protocols for situations in which health care resources are severely limited and patients are being given the most aggressive and expensive treatments, without pausing to consider if that is in their best interests — from their perspective.

In American medicine, the prevailing assumption is that more is better. But palliative care practitioners know that often that is not the case. An analytics team at the institute has been showing the real value in aligning what we do in terms of treatment with what people want. The work is also highlighting for senior leadership the important value of palliative care. It's helping us to support the case of expanding palliative care teams. Another advantage of doing this is that expansion can help alleviate the burden on clinicians outside of palliative care teams.

What are some of the roles palliative care practitioners have had during the pandemic?

When it comes to palliative care, it is less about fancy new drug treatments and more about the basics: helping patients understand the treatments for their medical condition, updating them on the physiological aspects of what is happening, and helping the patients and families stay in touch and feel connected.

During the pandemic some of the most poignant roles of palliative care team members have been just holding an iPad so patients and family members can visit, given the visitation restrictions of infection control protocols. They have been part of patient and family meetings. These can be emotional and painful conversations.

It is worth noting that our palliative care teams provide just-in-time resources to guide our non-palliative care colleagues in having conversations about patients' wishes, and we've been providing clinicians with tangible resources to facilitate communication as well as symptom management. It is important for frontline clinicians to have these resources.

In many ministries palliative care teams became involved in policy and protocol development to deal with critical issues such as visitation and the use of medical resources like personal protective equipment and ventilators. This invitation into operational leadership is occurring organically.

What are the main practical challenges to delivering on the promise of whole-person care?

Personal protective equipment has been essential but is obviously a physical barrier to touching patients and to being seen as a person by our patients. We have been sorely aware of the lack of family at the bedside and the difficulties with visitation. Even now, visits are limited to one or two family members. Before the pandemic we encouraged families to visit, bring children, and spend extended time with seriously ill and dying patients. This has been the most difficult strain of this situation.

Families of lower socioeconomic means, who are among those underserved by American health care, have suffered a disproportionate share of COVID-related sickness. I've met multigenerational families living in a single household in which everyone in the home was infected with COVID-19 and the matriarch and patriarch both died.

What have the limits of the pandemic meant for the delivery of palliative care?

It has been very hard to deliver on the full potential of palliative care to ease people's way. The constellation of factors we've discussed — the intensity of the disease and its often-rapid progression, the physical and social barriers required for safety, and our staffing challenges — all inhibited our abilities to provide care to our highest aspirations.

The fullness of human caring involves not just saving and prolonging life, but also doing what patients would value even if a cure is unlikely or impossible. These poignant times offer a chance for them to complete their lives, say things that have been unsaid, express forgiveness and love, and achieve a sense of well-being. People are more than just bodies; we can love, feel loved and experience moments of joy before we die. With our families we can honor and celebrate life and relationships. This is the fullness of life, that palliative care teams strive to preserve.

Now, we can't put lipstick on this pandemic pig. I wish it were otherwise, but many patients are not getting this comprehensive level of care because of the impacts of this pandemic. Palliative care practitioners have had an unflagging commitment to delivering the fullness of human caring and we've tried to do it in an innovative way. In aiming high, even during these difficult times, we have still been able to give really good care.

How are people dying during the pandemic?

Often, not as well as we would wish. We don't have the workforce to always hit the high mark we aim toward. But we've been doing the best we can. We have remained attentive to the dignity of our patients and their pain has been well treated.

Thankfully, we have not had to compromise on the fundamental elements of caring. There's been no shortages of essential medications to alleviate physical suffering. Patients are living and dying in clean, dry beds. We've been finding ways of connecting people within their families and of supporting those families in their emotional suffering and grief.

That is something we can be proud of, that we are continuing to honor their inherent human dignity and worth.