



## What is Palliative Care?

**Stephanie:** Welcome to Using Palliative Care in Bladder Cancer, a Patient Insight Webinar from the Bladder Cancer Advocacy Network. Before we begin, we'd like to thank Bristol-Myers Squibb, the EMD Serono-Pfizer partnership, Ferring, Genentech, Janssen Oncology, Merck, and Photocure for their support of the Patient Insight Webinar Series. I'm the Director of Education and Research at BCAN. I'm joined today by Dr. Elizabeth Wulff-Burchfield, otherwise known as Libby. She's an Assistant Professor in Medical Oncology and Palliative Medicine at the University of Kansas Healthcare System. Welcome, Dr. Wulff-Burchfield, Libby.

**Libby:** Just to give you a little outline, I'd like to start out by talking about some of the basics of palliative care, followed by some of the existing research, establishing the value of palliative care for people who have cancer. Then more specifically people with bladder cancer, look at some of the upcoming palliative care research that I think may change the game, and then circle back to how to access palliative care. Then we'll have time for questions.

Let's start by talking about palliative care basics. As many of you may be aware, I would say that the definition of palliative care has probably been less important historically than some of the connotations of palliative care. I think that our perception is our reality, and I certainly want to

The Evolving Palliative Care Definition by  
The Center for Advancing Palliative Care (CAPC)

- Palliative care, also known as palliative medicine, is specialized medical care for people living with a serious illness.
- Focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis.
- The goal is to improve quality of life for both the patient and the family.

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validate the importance of that. But I also think that it would probably be helpful to share some definitions and some of the nuances of palliative care as someone on this side of the stethoscope and who is a participant in this field.

One of the groups who has been most important to promoting palliative care has been CAPC, which is the Center for Advancing Palliative Care, as you gather in their name. Their definition is really the one that I think most people in my field turn to.

**Libby:** The first part of their definition would be that palliative medicine or palliative care, terms that we use interchangeably, is medical care for people who are facing a serious illness. The second part of our definition is that this form of medical care focuses on providing relief from symptoms, but also trying to just make quality of life better and removing barriers to that, whether that'd be symptoms, distress, caregiver burden. That's irrespective of the diagnosis that is causing those things to the patient's life and that of his or her caregiver.

The goal of palliative care is essentially to make sure that everyone is living their longest, best life, and that means patient and caregiver. Therefore, the third part of the palliative care diagnosis, the goal is to improve quality of life and make it as good as possible.

Something that I think is special about palliative care is the way that it is conducted. I really believe firmly that all branches of medicine are a team sport. I think oncology and urology really do exemplify that. But I think palliative care takes it almost to a different level.

The reason I say that is because palliative care really relies heavily on an interdisciplinary team and, believe it or not, one in which the doctor does not rule the roost. I think a lot of medicine has historically been structured, probably for worse, around the physician as a team leader. But in palliative care, we have a very, very flattened hierarchy, and the team is made up of physicians, nurses, as well as social workers, chaplain whenever possible, child life specialists whenever possible.

The Evolving Palliative Care Definition, cont.

- Palliative care is provided by a specialized interdisciplinary team:
  - Doctors
  - Nurses
  - Social workers
  - Chaplains
  - Child life specialists
  - And so much more, depending on the setting
- Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

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Forgive me for leaving advanced practice providers off of this list because they are certainly central to these teams. Then depending on the setting in which this given palliative care team is operating, there may be other specialties involved.

That really depends on the patient population who is being served by that team. I think if we have a palliative care team embedded in a neurology clinic where patients may have dementia, sometimes a bioethicist may be part of the team in order to really make sure that we're meeting the needs of the patient population and caregiver population we're serving.

The other thing I would emphasize, and that really does often get put in last as part of any palliative care definition, is that palliative care is appropriate for, as we say, any age, any stage. It can be provided alongside care that is given with the intent to cure.

I would imagine that there are people participating with this who has either been a patient or a caregiver for some incredibly aggressive treatment for any number of medical conditions. We all have either observed or experienced the burden that comes along with that. Therefore, palliative care is meant to help alleviate some of those burdens regardless of the intent of treatment.

Another set of interesting things about palliative care is that while a lot of specialties flow fluidly from inpatient to outpatient, outpatient palliative care and inpatient palliative care are very different, or almost sub-disciplines of the larger fields, and I'll explain what I mean by that.

But palliative care can absolutely be inpatient, outpatient, and sometimes in the home setting, but the makeup of the team is often different and the intent of the care is a little bit different between the settings.

**Libby:** The inpatient palliative care setting is the most common that we have in the United States. This is, again, interdisciplinary teams that often are a consultative team in the hospital or sometimes have specialized medical units, so palliative care units where care is provided to people who need us to help with symptoms.

But the other thing that's unique about this is that I would consider inpatient palliative care often focuses on crisis management and help us think about, again, what are the goals, what are the barriers, and then figuring out how to transition someone from life inside the hospital to life outside the hospital, because rarely is it that someone thinks life in the hospital is better than out. If it is, then that person is probably in trouble with a lot of things going on outside, and so we need to help their life be better.

**Nuances of the Palliative Care Setting**

- Palliative care can be delivered by specialists in multiple clinical settings, but inpatient is the most common setting in the United States
  - Inpatient consultation team
  - Palliative care units
  - “Crisis management” and assisting with transitions in care
- Outpatient palliative care is growing, but still much less common in the US
  - Often championed by and/or affiliated with another clinical program
    - Cancer center
    - Transplant/LVAD program
  - Cultivating a longitudinal relationship, providing anticipatory guidance

Outpatient palliative care occurs less frequently, at least at this time. This is rapidly changing. But this is still a little bit of a niche discipline, to be perfectly honest. What I would say is that while many fields, as I said, have this fluid inpatient to outpatient to inpatient to outpatient organic flow, outpatient palliative care often develops because of a champion from within another clinical program.

By that what I mean is that there will be clinicians or sometimes advocates or other staff members who are working within a clinical program such as a cancer center, or perhaps a lung, liver, heart transplant program or a left ventricular assist device program, a neurology clinic, et cetera, who sees some of the needs that their patients have and sees that they're lacking for solutions. Often that is where these programs develop.

What I can say is that at the University of Kansas Cancer Center, who has a pretty well-integrated palliative care program, if I may say so myself, our program was spawned because one of the bone marrow transplant nurses named Amy Velasquez thought that there were some needs that didn't really have a good solution at KU. She is really the person who spawned this program and still is a member of our team to this day.

**Libby:** Outpatient palliative care, unlike inpatient palliative care, we hope, won't be crisis management, but rather is something more focused on cultivating a long-term relationship with the patients, the medical team, and the caregiver team, whoever that is for each individual patient, certainly managing barriers, managing symptoms, helping with communication, but also providing anticipatory guidance.

Many times people with serious illnesses, we can predict it that they may have progression of that illness over time or may have clinical deterioration over time. Therefore, we can help predict what the road ahead may look like and make sure that the medical care people are getting and the support that they're getting is a good fit for what matters to them regardless of where we are on the journey.

Palliative Care versus Hospice - Similar but Different	
 <p><b>Palliative Care</b></p> <ul style="list-style-type: none"> <li>• Patients of all ages and with any diagnosis or stage of a serious illness</li> <li>• Hospitals and outpatient clinics (mostly), also sometimes at home</li> <li>• Physician and advance practice provider fees covered by Medicare part B for inpatient/outpatient care, part A for hospital fees.</li> <li>• Given alongside routine medical care</li> </ul>	 <p><b>Hospice</b></p> <ul style="list-style-type: none"> <li>• Patients of all ages who have life expectancy of &lt; 6 months if illness follows its natural course</li> <li>• Home (mostly), also inpatient hospice facilities ("hospice house") or residential hospice facilities</li> <li>• Covered by Medicare hospice benefit</li> <li>• Patients must <b>forego</b> life-prolonging treatment directed at primary illness</li> </ul>

Commercial payors usually follow suit

A lot of times the elephant in the room, when talking about palliative care, is hospice. I think it can be helpful to compare and contrast palliative care and hospice. What I will say is that when I describe palliative care and hospice to my patients, I describe hospice as a special form of palliative care, which I think is true, but there are some pretty important differences.

First, when we think about palliative care and hospice, the things they have in common are that patients have ... This can be for patients of any age, any stage, of course. At hospice, well, that is true theoretically that it could be any age in any technically defined stage. The one criteria, and that's actually required for hospice referral and participation, is that the patient needs to have a life expectancy of six months or less predicted by two physicians if their illness follows its natural course.

Some other differences are the setting. I'm sorry, my slides haven't translated perfectly, but what you can see is that palliative care, as I mentioned, that happens in hospitals and outpatient clinics mostly, sometimes at home. While palliative care is in hospitals, clinic, and sometimes at home, hospice actually mostly takes place at home. About 85% of hospice, at any given time, at least in the US, are taking place at patients in their home settings.

Now if they live in a nursing facility, that means that is the home setting for that person. But there are also inpatient hospice facilities, or sometimes called hospice houses, the intent of which is to manage symptoms that can't be controlled in the home setting.

Sometimes there are also residential hospice facilities, which are, to be perfectly honest, a really confusing concept for someone, for even medical personnel. But the way we usually think about it is some hospice facilities or hospice houses have beds that are for patients who really need nursing home-level care and would be paying out-of-pocket for that regardless, but also qualify for hospice and are choosing to live in that facility.

That's pretty nuanced and not every hospice agency can provide that. Medicare does not require that hospice agencies are able to provide that level of care.

In terms of the finances, palliative care is just another specialty of medicine. Just as specialty care for dermatology or cardiology or nephrology would be covered by the inpatient side on Medicare part A, Medicare part B for outpatient care, the palliative care has that same payment structure, whereas hospice is very different because it's really an all-inclusive Medicare benefit.

What's interesting and wonderful about that, and sometimes tricky, is that the hospice benefit pays for everything on medical care, all medications, all supplies, any lab tests or x-rays or any of those things that are needed to help someone live their best life. That pertains to the symptoms and medical burden related to their primary diagnosis.

What that means is that, again, any supplies, be it a shower chair, all the way down to your medicines, your oxygen, et cetera, is all covered. Generally, commercial payers will follow suit, or the same coverage policies, although there, unfortunately, are commercial payers that don't cover hospice, which is very rare.

Then, finally, when we think about another important distinction between palliative care and hospice, almost all palliative care is care provided alongside regular medical care, whatever the patient needs for the rest of their health condition.

Again, if someone has cancer, then they're going to be seeing their oncologist, their radiation oncologist, maybe their surgeon, depending on what their needs are. Palliative care does not threaten that. It doesn't undermine it. It doesn't take it away in any form or fashion. It just adds to it.

Hospice is different. Hospice is meant to be holistic care, not just based on physical needs, but emotional, psychosocial, and spiritual needs.

Because of that, patients who are enrolled in hospice have to forego life-prolonging treatment that is directed to their primary illness, and related to their overall prognosis related to that, that primary illness and their overall trajectory.

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