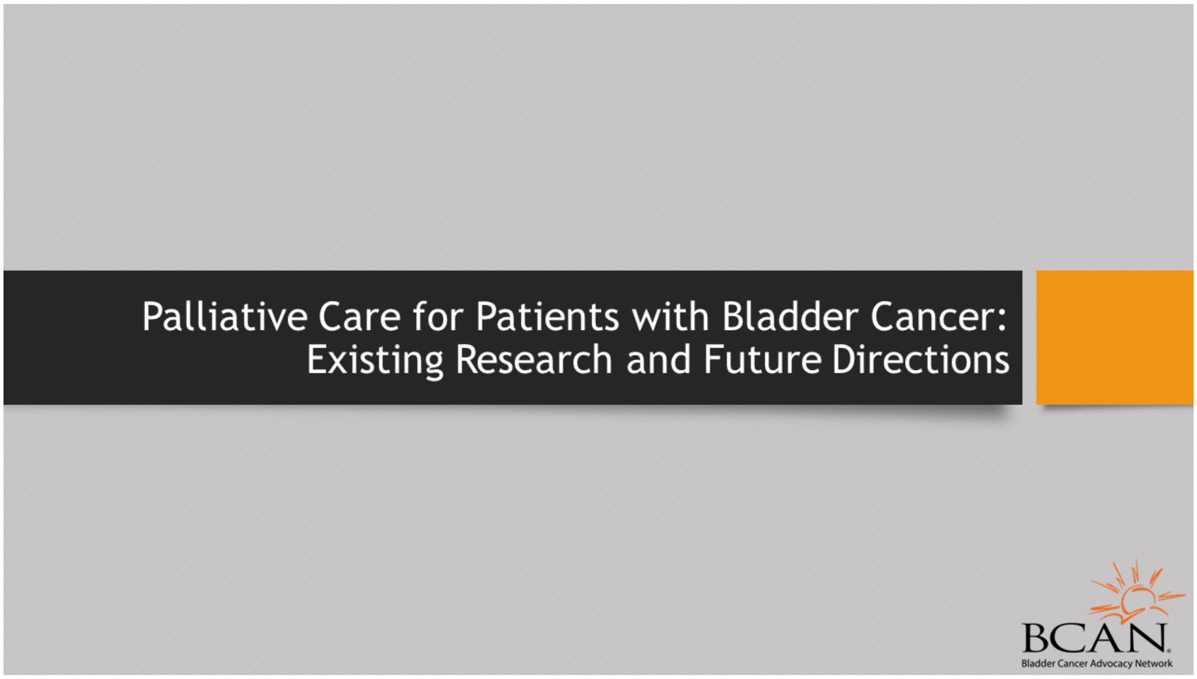
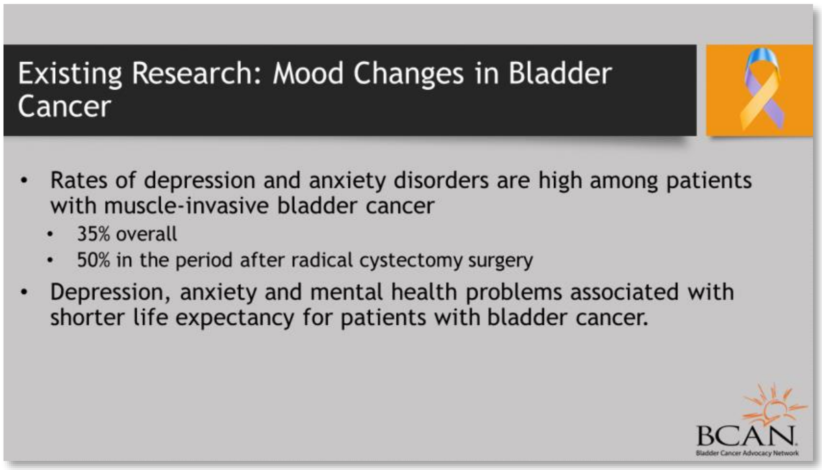


Palliative Care for Patients with Bladder Cancer: Existing Research and Future Directions

Research in Palliative Care

Libby: Next, I'd like to pivot into talking about palliative care, some aspects of palliative care and some data about palliative care that is specific to people who've been diagnosed with bladder cancer. As some of you probably have experienced firsthand, and some secondhand as either caregivers or clinicians, researchers, rates of depression and anxiety are, unfortunately, very high among people who have muscle-invasive bladder cancer.

I do not, in any way, mean to suggest that that is not the case for people who have non-muscle-invasive bladder cancer. It's just that that data is really being gathered still. I have no doubt in my mind, based on my professional experience, that patients who have non-muscle-invasive bladder cancer will also be shown to have similarly elevated rates of depression and anxiety, but that data is forthcoming.



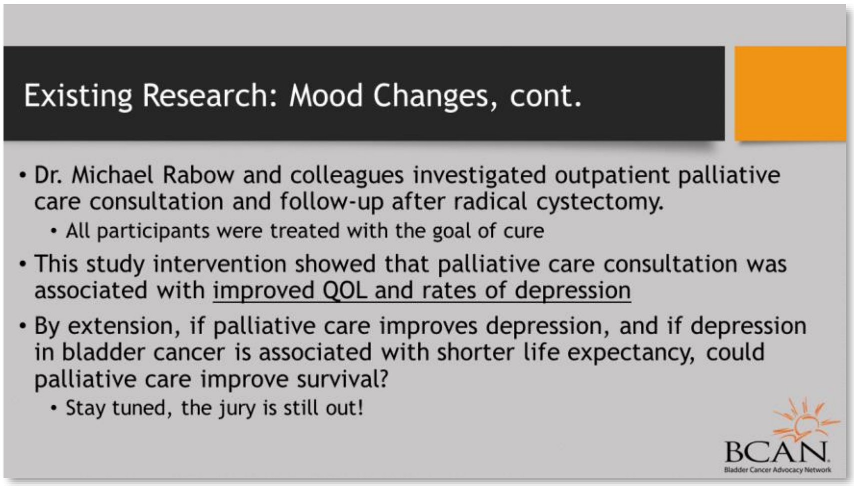
Existing Research: Mood Changes in Bladder Cancer

- Rates of depression and anxiety disorders are high among patients with muscle-invasive bladder cancer
  - 35% overall
  - 50% in the period after radical cystectomy surgery
- Depression, anxiety and mental health problems associated with shorter life expectancy for patients with bladder cancer.

But these are pretty high rates. When we look at the trajectory of the entire cancer journey, there's a 35% chance of patients having depression or anxiety. In the period after radical cystectomy, it's actually a 50% chance. The other data that's pretty powerful is that depression, anxiety, and other mental health conditions are associated with shorter life expectancy for patients with bladder cancer.

So Dr. Michael Rabow, who is a clinician at the University of California at San Francisco, and his colleagues conducted a research study to investigate the impact of outpatient palliative care consultation and follow-up after radical cystectomy.

The patients on this study were folks who were getting treatment with the intent to cure. The study intervention was essentially palliative care consultation after their radical cystectomy. Excuse me, I'm getting a little popup box. And consisted of that, plus follow-up.



Existing Research: Mood Changes, cont.

- Dr. Michael Rabow and colleagues investigated outpatient palliative care consultation and follow-up after radical cystectomy.
  - All participants were treated with the goal of cure
- This study intervention showed that palliative care consultation was associated with <u>improved QOL and rates of depression</u>
- By extension, if palliative care improves depression, and if depression in bladder cancer is associated with shorter life expectancy, could palliative care improve survival?
  - Stay tuned, the jury is still out!

When they looked at the outcomes of the study, it demonstrated that outpatient palliative care consultation following radical cystectomy was associated with improved quality of life, sort of a global quality of life measure, as well as better rates of depression.

I think the question that many of us are asking is that if palliative care improves depression for patients who are dealing with bladder cancer, and if depression is associated with worse life expectancy, does that mean that palliative care might improve survival?

Well, I think it actually might, personally. That data does not exist right now. That's something that I think probably will be forthcoming in the next few years because that question has captured the interest of many. But I think the jury is still out at this time.

Existing Research: Integrated Palliative Care with Urology

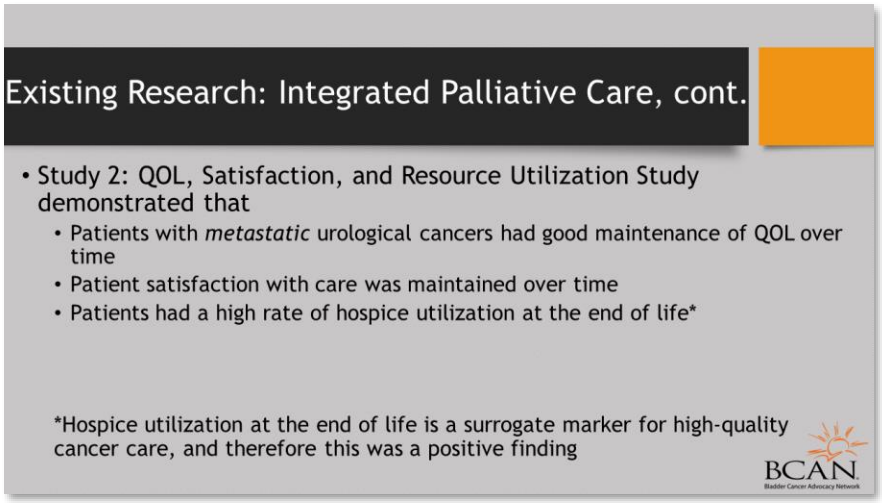
- Clinician-investigators at the Greater Los Angeles Veterans Affairs hospital have published two studies about their practice consisting of palliative care integrated within a urology clinic
- Study 1: Interview-based study demonstrated that
  - This integration was feasible
  - Palliative care collaboration improved quality of care
  - Palliative care referral did not add significant additional time or work for urologists
  - Palliative care involvement helped urologists have a better sense of the "whole patient" and had positive impacts on treatment decision making.

Some other research that I'd like to share that is specific to patients who have bladder cancer is some data that has been generated by a group at the Los Angeles VA Hospital who have published a few studies about their unique practice that consists of a palliative care clinic embedded in a urology clinic.

The first study was really an interview-based study with clinician, but that showed that the intervention, meaning the integration of palliative care within a urology clinic, was feasible, it wasn't difficult to do, that the palliative care collaboration with urology improved quality of care in the mind of the urologist, that palliative care referrals did not make their life harder.

While that may not seem that important, I think if we're trying to sell any group of clinicians on any intervention, we want to make sure they know that it either won't make their lives harder or if it will make their life harder, that it's really worth it. In this case, they found that it not only was it worth it, but it didn't make their lives harder.

Then, finally, the clinicians involved felt that they had a much better sense of the whole patient's ... Sort of the holistic view of the patient and caregiver team as well as what their goals were, and that they were more satisfied with the decisions that they were making in conjunction with their patients.



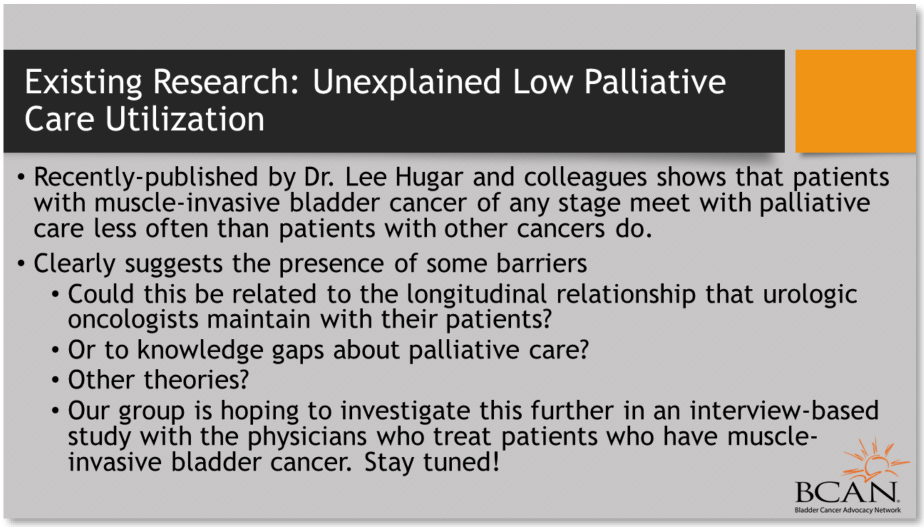
Existing Research: Integrated Palliative Care, cont.

- Study 2: QOL, Satisfaction, and Resource Utilization Study demonstrated that
  - Patients with *metastatic* urological cancers had good maintenance of QOL over time
  - Patient satisfaction with care was maintained over time
  - Patients had a high rate of hospice utilization at the end of life*

*Hospice utilization at the end of life is a surrogate marker for high-quality cancer care, and therefore this was a positive finding

The next study was one that was looking at quality of life, patient satisfaction, and resource utilization. This was focused on patients who had metastatic urological cancers, including bladder cancer. But one important impact is that the patients who had the palliative care intervention had excellent maintenance of quality of life over time. They also reported really high satisfaction and trust in their care.

Finally, that patients had high rates of hospice utilization at the end of life. While I think reading that, in conjunction with these other findings, might seem, I don't know, a little ghoulish or negative, in a lot of ways, that is a very high-quality metric in the medical community, particularly the oncology community, because what we've learned is that if patients do have the support of hospice at the end of their life, then often patients get to have an end of life that's consistent with what they would hope for and what their families would hope for. Hospice utilization is actually a surrogate for really high-quality cancer care. So this was actually a really good finding.



Existing Research: Unexplained Low Palliative Care Utilization

- Recently-published by Dr. Lee Hugar and colleagues shows that patients with muscle-invasive bladder cancer of any stage meet with palliative care less often than patients with other cancers do.
- Clearly suggests the presence of some barriers
  - Could this be related to the longitudinal relationship that urologic oncologists maintain with their patients?
  - Or to knowledge gaps about palliative care?
  - Other theories?
  - Our group is hoping to investigate this further in an interview-based study with the physicians who treat patients who have muscle-invasive bladder cancer. Stay tuned!

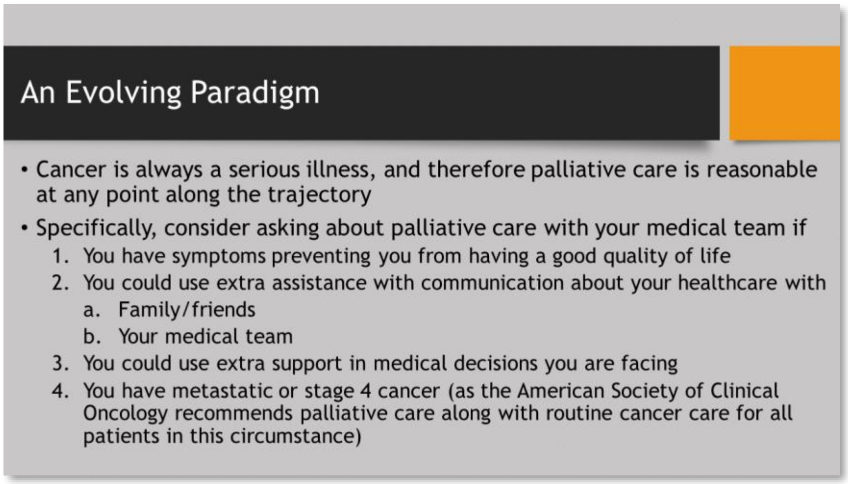
Some other existing research that's really high impact is that recently published work by Dr. Lee Huger and colleagues has shown that patients with muscle-invasive bladder cancer of any stage meet with palliative care less often than patients who have other cancers. We don't have the answer here, but it clearly suggests that there are some barriers here that are getting in the way of palliative care consultation when it's appropriate.

I think he and I are putting a lot of thought into what could be going on. The one theory we have is that could it be that this is related to the longitudinal relationship that urologists have and urologic oncologists have with their patients?

Some surgeons don't end up in the setting of other cancers. Not all surgeons need to follow or do follow their patients over the long term.

Therefore, we have hypothesized that maybe that because urologists maintain these close relationships, maybe that it's decentralizing the decision-making structure and leading oncologists to wonder whether it is appropriate. Could it be that some clinicians that's part of the healthcare team have some misconceptions about palliative care or knowledge gaps? They don't understand how to use it and when to use it.

Libby: Certainly, we have had some other theories as well, but our group is trying to investigate this. He's doing an interview-based study because, for better or worse, most of the time for palliative care access, the current structure is that typically patients get referred to palliative care, although that is usually not required. But we're trying to figure out where the barriers are and then figuring out ways to overcome them. So stay tuned. I hope to have exciting data to share with you in the near future.

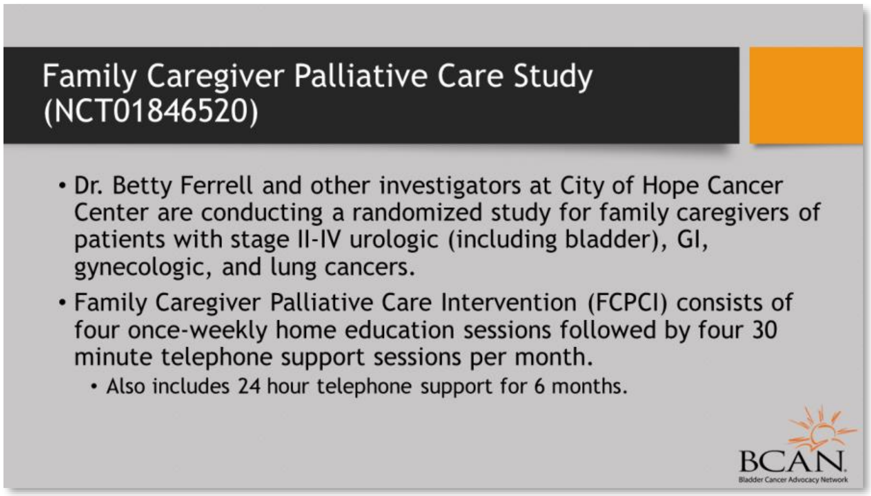


An Evolving Paradigm

- Cancer is always a serious illness, and therefore palliative care is reasonable at any point along the trajectory
- Specifically, consider asking about palliative care with your medical team if
  1. You have symptoms preventing you from having a good quality of life
  2. You could use extra assistance with communication about your healthcare with
     a. Family/friends
     b. Your medical team
  3. You could use extra support in medical decisions you are facing
  4. You have metastatic or stage 4 cancer (as the American Society of Clinical Oncology recommends palliative care along with routine cancer care for all patients in this circumstance)

What I wanted to leave this section with is thinking about ways, triggers, or times when it might make sense to consider asking one's clinician about palliative care. Cancer is always a serious illness. There is no case of cancer that is "a good cancer" or "an easy cancer". That does not exist. I think palliative care is really appropriate at any point across the cancer trajectory.

Some specific times that I would recommend that either my patients or anyone participating in this as a patient and advocate, a caregiver or a clinician, thinking about when it makes sense would be if you or the patient have symptoms preventing you from having a good quality of life. If you have some communication barriers with either your healthcare team or your loved ones about what you're hoping for in your medical care. If you just need some extra support when it comes to some of the medical decisions that you're being asked to make. Or if you have metastatic or stage four cancer, because all patients who have metastatic or stage four cancer are recommended to have palliative care consultation along with their routine cancer care.

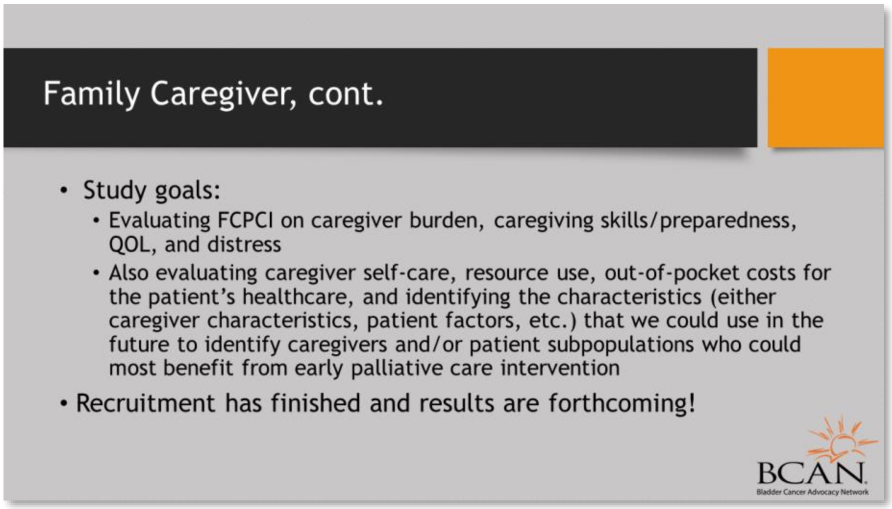


Family Caregiver Palliative Care Study (NCT01846520)

- Dr. Betty Ferrell and other investigators at City of Hope Cancer Center are conducting a randomized study for family caregivers of patients with stage II-IV urologic (including bladder), GI, gynecologic, and lung cancers.
- Family Caregiver Palliative Care Intervention (FCPCI) consists of four once-weekly home education sessions followed by four 30 minute telephone support sessions per month.
  - Also includes 24 hour telephone support for 6 months.

Next, I'd like to share some really exciting ongoing palliative care research that I think really has the potential to make waves in wonderful ways going forward. First, I'd like to share with you some information about the Family Caregiver Palliative Care study. I included the NCT number that you can use if you'd like to go to clinicaltrials.gov and read more about some of the endpoints being studied with the study.

Dr. Betty Ferrell, truly a giant in the world of palliative care researcher, and other investigators at City of Hope have been conducting a randomized study that's focused on family caregivers for patients who have stage two through four urologic, GI, GYN, and lung cancer. Bladder cancer's certainly included in that.



Family Caregiver, cont.

- Study goals:
  - Evaluating FCPCI on caregiver burden, caregiving skills/preparedness, QOL, and distress
  - Also evaluating caregiver self-care, resource use, out-of-pocket costs for the patient's healthcare, and identifying the characteristics (either caregiver characteristics, patient factors, etc.) that we could use in the future to identify caregivers and/or patient subpopulations who could most benefit from early palliative care intervention
- Recruitment has finished and results are forthcoming!

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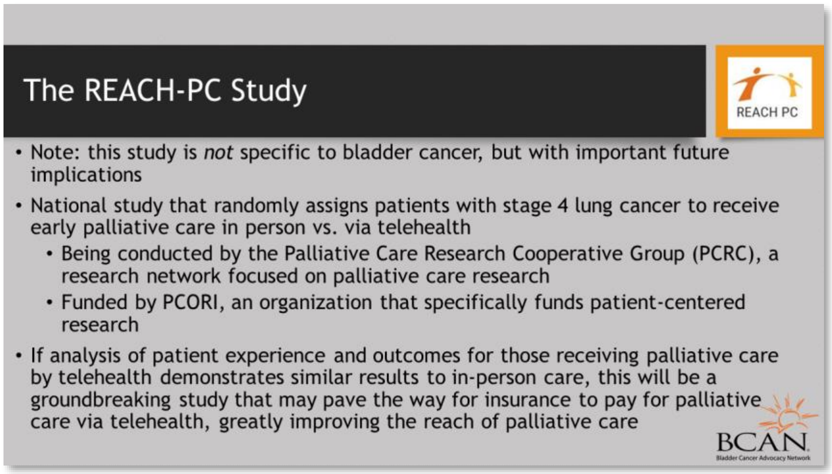
The nature of this intervention is that at the time of diagnosis, the caregiver, which is usually a family member, so either a spouse, a child, a parent, a sibling, et cetera, gets randomized to either get regular care with their oncologist or that plus the addition of a once weekly home education session followed by half hour telephone sessions. Then also 24 hour telephone support with the palliative care team for six months.

The outcomes that are of interest here are looking at the impact of this family caregiver intervention on caregiver burden and caregiver skills and preparedness, caregiver quality of life and caregiver distress.

Also, some other endpoints that are of interest to Dr. Ferrell and her colleagues are looking at caregiver self-care, their use of resources, out-of-pocket costs, and then trying to look at the characteristics of patients or caregivers that seem to benefit the most from this intervention, because sometimes what we find is that subpopulations really do benefit more than doing something as a blanket intervention. That's something else they're looking at.

Recruitment has finished, but that's actually good for us because that means that results are forthcoming. I personally would expect that what we'll see is that caregiver burden and quality of life is better with this extra layer of support.



The REACH-PC Study

REACH PC

- Note: this study is *not* specific to bladder cancer, but with important future implications
- National study that randomly assigns patients with stage 4 lung cancer to receive early palliative care in person vs. via telehealth
  - Being conducted by the Palliative Care Research Cooperative Group (PCRC), a research network focused on palliative care research
  - Funded by PCORI, an organization that specifically funds patient-centered research
- If analysis of patient experience and outcomes for those receiving palliative care by telehealth demonstrates similar results to in-person care, this will be a groundbreaking study that may pave the way for insurance to pay for palliative care via telehealth, greatly improving the reach of palliative care

BCAN
Bladder Cancer Advocacy Network

Another study that's really exciting is the REACH-PC study. I want to be totally honest and tell you this is not actually specific to bladder cancer. Instead, it's actually for patients who have metastatic or stage four lung cancer. However, I think it has really exciting implications that can impact the way that palliative care is provided to patients with bladder cancer. That's one of the reasons I wanted to share.

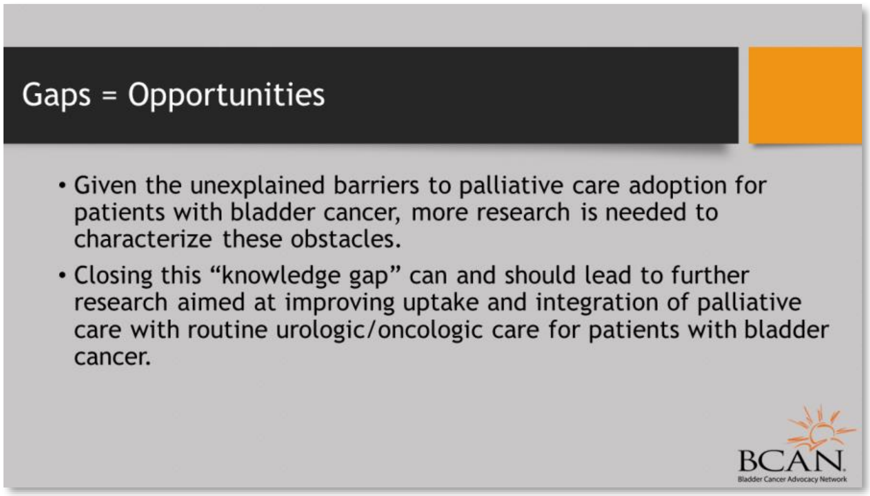
The REACH-PC study is a national study that's being conducted through the Palliative Care Research Cooperative Group, which is a clinical trial network. It randomly assigns patients with stage four lung cancer who, as we now know, should all be getting palliative care to either get palliative care and clinic or palliative care via telehealth. This particular telehealth intervention is a video palliative care intervention, something akin to Skype or FaceTime, those sort of telehealth type visits.

This is funded by an organization that focuses on patient-centered research. This isn't specific to patients dealing with bladder cancer, so I don't want to spend too much time on it. But I do want to mention that if the analysis of this trial shows that the patient experience and that the outcomes associated with palliative care seems to be the same for the people who got it in clinic and those who got it via telehealth, then I think this could absolutely be a game-changer for the way that payers, so Medicare and commercial payers and also government insurance of other types, pay for a telehealth visit. That could dramatically change one's ability to access palliative care.

When I think about my own patient population in my oncology clinic, this, I think, speaks volumes to me because based on the data that Dr. Rabow has established, that palliative care following radical cystectomy helps with quality of life and depression for patients with bladder cancer, I know that many of my patients with bladder cancer drive very long distances across the state of Kansas to come to the University of Kansas because we have surgeons who have great expertise in bladder cancer-related surgery. Therefore, it is too burdensome for them to drive five hours to come see me or one of my colleagues in palliative care.

But if we could pay for palliative care visits via telehealth, then institutions would be motivated to set aside time for telehealth visits, for palliative care and other disciplines too potentially, to help support patients and caregivers better. I think this is something that I wanted to put a bug in your ear about because I think this could be a pretty monumental study.

The lead investigator of the study is Jennifer Temel, who is the person who has probably had some of the most influence in the palliative care research over the past decade.



Gaps = Opportunities

- Given the unexplained barriers to palliative care adoption for patients with bladder cancer, more research is needed to characterize these obstacles.
- Closing this "knowledge gap" can and should lead to further research aimed at improving uptake and integration of palliative care with routine urologic/oncologic care for patients with bladder cancer.

I tried to be a glass half full person, but I want to say that I think there are lots of opportunities to help look at the relationship between palliative care and bladder cancer. One of those that speaks the loudest to me is that there clearly are barriers to palliative care uptake for patients who have bladder cancer. We need to figure out what these barriers are and find ways to make them better.

Closing this gap in knowledge could lead to ... If we can figure out what some of the barriers are, then further research could take place to find ways to integrate palliative care better for patients with urological cancers, including bladder cancer, and to help get patients every bit of support from the healthcare team, including the palliative care team, that is possible, so they can live their best life the longest amount of time possible.

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