

# Meet the Expert: Lillie Shockney, RN, MAS



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Lillie Shockney, RN, MAS

## Meet the Expert

Discussions with patients with cancer who are facing metastatic disease progression must be handled with empathy and compassion. In this interview, Lillie Shockney, RN, MAS, the University Distinguished Service Professor of Breast Cancer and a professor of surgery at the Johns Hopkins University School of Medicine, shares her approach to handling delicate end-of-life conversations with her patients.

The interview below has been edited for clarity and length. The full conversation can be accessed using the QR code provided.

## Interview

**Joelle Hamilton, MD:** Thank you for joining us today for our second Meet the Expert session with our guest, Professor Lillie Shockney. I'm Joelle Hamilton, a medical oncologist in Birmingham, Alabama, with Urology Centers of Alabama, which is a large urology group, part of the LUGPA affiliation, where we are privileged to care for individuals with benign urologic issues as well as early cancer and advanced cancer with a multidisciplinary approach of urology, medical oncology, and radiation oncology. I'm delighted and flattered to be able to be part of this journal and to be a contributing editor of *Reviews in Urology*.

Our guest today is Professor Lillie Shockney, University Distinguished Service Professor of Breast Cancer and a professor of surgery at Johns Hopkins University School of Medicine. She's the co-developer of Work Stride, [an initiative to manage] cancer at work, at Johns Hopkins HealthCare Solutions; cofounder of the Academy of Oncology Nurse & Patient Navigators; and cofounder of the Association of Chronic & Complex Care Nurse Navigators. Welcome, Professor Shockney—Lillie.

**Lillie Shockney, RN, MAS:** Thank you so much for having me. I imagine our audience might be a little confused with my specialization in breast cancer, but I also specialize in [working with] patients with any kind of cancer that they're dealing with, which is stage IV. So [we're] looking at metastatic disease, sometimes we call

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it *advanced cancer*, and even helping people with planning end-of-life [care].

**Dr Hamilton:** Please describe how you communicate with compassion difficult news such as cancer progression.

**Professor Shockney:** It is critically important for the physician to be honest with the patient. That's an expectation that patients have, which has been clinically studied and published: They don't want to have something sugarcoated. They also don't want you to avoid just how bad things might be.

So first, when we're entering the room, we should not look rushed. I like to sit close to the patient, but certainly do not remain standing. Give good eye contact. This is a conversation that needs to be zeroed in on that patient's face. So, tell the patient something like this: "When you had cancer several years ago, we believed that it had been effectively treated, [but] as we discussed back then, there are situations in which treatment doesn't work as we had hoped and believed.

"Cancer cells can travel, as you know, to other parts of the body. They can use the lymph nodes; they can use the bloodstream to move from where they started to another organ site. And as a result of that, and with the symptoms that you had, we took some more pictures to see what was going on . . . [and] unfortunately, the situation that you're facing and I'm facing with you is that you do have metastatic cancer now, and it is in your bones."

**Dr Hamilton:** I really appreciate how you brought in the part that you're with the person and part of their team because I imagine at that point in time, that [news] can be not only very shocking and traumatic but very isolating.

**Professor Shockney:** Once I say those words, "You have metastatic cancer," I pause because that is a shock to hear those 2 words now together. And actually, for me, it's a 15-second pause so they can absorb the news.

And then I'll pick up from there, and I'll say, "So, our plan this time needs to be to treat this disease as a chronic illness. Our mission before was to have you be cancer free. That's not something that we're going to be able to have as our goal of care this time. We're going to treat this as a chronic illness, and you and I are going to have a long-term relationship."

[Then I say], "I want to make sure that we are preserving your quality of life. Quantity of life is not the goal. Quality is. I don't want you feeling miserable in just existing because of some treatment I've put you on, and you say, 'Gee, this is a hell of a way to live.' Because that's wrong, and that would be my fault, but I'm only going to know that if you and I communicate well together."

**Dr Hamilton:** I really appreciate how you talk about not only quantity . . . but really how a person feels [their] quality of life [is]. So not only the disease process but also the treatment and the impact there. That's really important.

**Professor Shockney:** It is. When I'm in a conference listening to a physician doing a lecture on the results of a clinical trial, and that doctor will say, "As you see with drug X, the patient lived 5 months longer, and with drug Y, they only live 2 months longer." I'm that annoying person in the audience that puts their hand up and says, "Were they living or were they existing? I want you to lay on top of that chart what side effects this patient was experiencing, because if they're sick as a dog and they're home in bed and they miss their son's high school graduation, then we have failed them." And that always makes the room very quiet.

**Dr Hamilton:** I just want to sit on this for a second: Living with cancer is different than existing with cancer.

**Professor Shockney:** Yes. It really is. We're taught to treat the disease, and so as long as there's another treatment, we're going to say, "Here's the next treatment." But we really need to step back . . . [and consider] if we were the patient, how would we want to experience all this? How would we want to be spoken to? How involved would we want to be in the

decision-making about treatment decisions? And how would we want to have great emphasis on our quality of life? That needs to be the priority.

**Dr Hamilton:** Absolutely. If you can, please share a little bit about talking to a person [who is] transitioning from, say, an active treatment to more quality-of-life care.

**Professor Shockney:** Sure. [In] patient-centered care . . . we must respect the patient's previous experiences in their life, what they value, and [their] needs and preferences in care planning, coordination, and delivery. When we do that, it's actually statistically proven to improve outcomes for our patients: [There are] better use of resources . . . decreased costs, and actually an increase in satisfaction with their care.

So after we've done introductions and I've explained to the patient that I specialize in the kind of cancer that they have, I ask . . . "How much do you want to know about your cancer?" Some people want to know everything, and other people want what I call "just-in-time information" . . . because it's just too much for him or her to cope with at that time.

Then [I ask,] "What are you hoping for right now? What are you most worried about currently? Tell me 3 things that bring you joy." Those 3 questions I will ask every time I see that patient because the answers will change over time.

I also want to know, What are the upcoming milestones that are going to be happening in this patient's life over the next [several] months? Is their daughter getting married? Is their grandson graduating from college? Do they have a 25th wedding anniversary themselves?

And I ask that because I want to preserve those milestones. I don't want them feeling like crap, so we may do a drug holiday then.

Sometimes people will say, "Those things don't matter anymore. Please just get me better," and I'll say, "In retrospect, these are going to be really

important not just to you but to your family. Don't give cancer any more of you than we absolutely need to give it. I don't want it stealing away these kinds of milestones."

**Dr Hamilton:** Exactly. If you're sitting there and you're thinking about treatments and possibly the future and what to expect, what I'm hearing is [that we should focus on] meaning and purpose.

**Professor Shockney:** And then the final phase, we hope, is to experience a good and peaceful death. There are very specific elements that all of us must go through in order to experience a good and peaceful death.

**Dr Hamilton:** I want to thank you for . . . [sharing guidance on how to] care for the person that's directly in front of us and to see them as who they are, to have really patient-centered decisions and care.

**Professor Shockney:** To speak for a moment about hospice and palliative care, if I may, [one] reason why patients will decline hospice is they don't want to be abandoned by us. We've been taking care of them. I know them. They know me.

So instead of saying, "I'm transferring you to hospice, this is the last time we'll be seeing each other," I'll ask the patient, "It would be a privilege if you allow me to stay in touch with you and your family as you continue your journey on end-of-life [care]. Is that OK with you?"

Big sigh of relief out of that patient's mouth. Family's also relieved. And I'll say, "I'm not in charge of your care, but I'm a touchstone because you and I have bonded together, and I want to be with you to the end of this journey." [With that approach,] they will sign up right away absolutely, positively for hospice.

**Dr Hamilton:** Yes, yes.

**Professor Shockney:** [Finally,] I want all of you who are listening today to stop saying, "I'm so sorry I couldn't save your life." We're not helping the patient

by saying that. We're not helping ourselves by saying that. I want you to be able to instead say, "I want to reflect back over our time together. I remember how scared you were when I sat down to tell you that you had advanced cancer, and we've gone through 10 lines of therapy together. You made it very clear to me what criteria you wanted to use to transition, to regain control of your life, and to receive your care at home. You've shared stories with me about your family, and I've really taken them to heart. I'll share those stories with other patients because those are valuable resources and ways of communicating that you've taught me. I respect where you are, and I wish for you [the fulfillment of all the] elements of a very peaceful death. And I will pray that that happens for you."

That's the conversation I have, and it makes me feel, frankly, good because I did what a clinician should do for this patient. And I'm not going to say, "I'm so sorry I couldn't save your life," because if I say that, they're going to go, "Does that mean she could have? Did I get the wrong drugs? Was I in the hands of the wrong doctor?"

We don't want to be placing doubts in somebody's mind when they're just days away from dying. We need to take pride in what we did for them. We really do.

**Dr Hamilton:** [Thank you for illustrating ways to

approach] conversations that allow us to be part of our patients' specific process for their chosen and peaceful death. I know that this is going to be something I not only read but listen to multiple times. So, thank you.

**Professor Shockney:** Thank you. Thank you.

### Article Information

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