TARLISE TOWNSEND: Hi, everyone. Thank you for joining us today and thank you to ASCO for inviting me. So, I'm just going to talk.

When I was diagnosed with stage 4 melanoma in 2019, I had a lot of questions about how to integrate this new information into my conception of my future. Because I'd been diagnosed at stage 3 four years earlier, I'd already done some work to come to terms with the possibility of my life being cut short by cancer. But, in order to adapt to the sudden news of progression after four years of no evidence of disease, it felt necessary to have some sense of what it was I was adapting to.

What kind of trajectory do people with this diagnosis typically follow? What's the range of likely outcomes? I kept bringing up questions along these lines in my doctors' appointments. So, for example, I was in graduate school at the time, and I wanted to know, am I likely to have time to finish my PhD, or should I just drop it all and travel around the world? Should I recalibrate any hopes for having children one day? Should I bother dating, or is that just cruel if all I can offer someone looking for a serious relationship is extended suffering followed by certain death just around the corner?

I also had questions about the suffering itself. I knew that a lot depended on where the cancer ultimately spread, but I didn't know what the range of likely outcomes looked like. In terms of pain and suffering, what's the best-case scenario? What about the worst? How much can be done to minimize pain throughout the process, and how much suffering is just a given?

Of course, I recognize that, while we all want to be able to tell the future, most of the time, our health care team can't do that for us. Nor can they make these important life decisions for us. But by providing a clearer sense of what we do and don't know about a diagnosis and its implications, they can provide some of the scaffolding that's necessary to make those decisions and to come to terms with what may lie ahead.

But instead, I found that many, though not all, of my clinicians would evade these questions. *We're eternal optimists here*, one clinician would say any time I'd bring a question like this up, before changing the subject. Others would deflect by highlighting the outliers they've seen. *Hey, I had one patient on this drug for more than five years.* I know this was meant to make me feel better, but instead, it left me feeling in the dark, patronized, and not privy to the richer and more nuanced understanding of my disease that my care team had access to.

They were trying to protect me, but instead I felt underprepared and under-informed. In fact, a recent study in *JAMA Network Open* revealed that this optimistic future talk, as the authors term it, is a key way in which oncologists deflect discussions related to end of life. Other research has found that far too few oncologists ever document end-of-life care discussions with patients with advanced cancer, even though national guidelines recommend such conversations when life expectancy is less than one year. This, of course, can lead patients to pursue toxic treatments longer than makes sense. It can reduce the likelihood that they'll have serious conversations with loved ones about how

to make medical decisions in line with their wishes and values, and it can diminish a patient's ability to come to terms with what may lie ahead.

Now, I don't think that I personally have fallen within that one-year life expectancy window yet, but based on my experience, at seems that the tendency to avoid or deflect, particularly in response to concerns about the future explicitly raised by the patient, are probably not unique to that end-of-life setting, and maybe just as problematic for all patients as we try to live well amid cancer.

I ended up doing a lot of my own death work, as I call it, reading the peer reviewed literature on my disease and talking to my clinician friends about their understanding of the latest advances. I read books like *Being Mortal* and *Advice for Future Corpses*, and wrote letters to my health care proxies and other loved ones to help them guide both end-of-life and after-life decisions. And finally, I give a lot of thought to how I want to spend the time I have, grappling with the fact that, at age 30, my life could take multiple very different paths-- at one extreme, many decades of a rich career, a loving relationship perhaps, countless travel adventures; at the other, a short amount of time, followed by maybe an abrupt end.

And what I found is that, rather than leaving me more scared, facing death head on has left me feeling calmer and more prepared for whatever comes. In fact, I got to test this out most explicitly on March 2020, when I was hospitalized for what was thought to be COVID, but what turned out to be interstitial lung disease caused by checkpoint inhibitors. On my second day in the hospital, I decompensated, and the ICU nurse was sent to brief me on intubation. It's hard even for me to believe it, but as I grappled with the news that I might be intubated overnight and not wake up, I was at relative peace. I truly can't imagine how it would have felt if I hadn't done that death work in advance.

So, my request for you all is please, don't deflect when patients raise questions and concerns about what's to come. Be open to exploring their fears and eliciting their values. Empathize with them, provide what information you can, and be ready to integrate what you learn from these conversations into your treatment recommendations. Thank you.

Video: https://drive.google.com/file/d/1exQvYcS_XCfMlT1_8awSisWMT1rAkSqV/view