

Panel Discussion—Feedback and Q&A

Participant

As patients and advocates, when we deal with doctors and talk about the problems, oftentimes the answer is don't worry about it now. If it happens, we will fix it. I don't think enough answers are given up front. More information up front will assist patients with expectations and satisfaction.

John Hairston, MD

These things are hard to do. We don't have a crystal ball that tells us where patients are on a spectrum, but fellow patients can be my biggest advocates. Only a fellow patient is going to be able to relate to what patients are going through and what to expect. We don't have all the answers that patients want, but we do try to get everyone involved on the front end in a multi-disciplinary environment.

Participant

One of the big problems is when a patient is diagnosed with prostate cancer we do explain many of the problems they may potentially face, but many of them don't make connections with others who have experienced those problems. Even if you addressed it initially, they are completely focused on the prostate cancer diagnosis and may miss the details.

Mr. Anant Kulkarni

The first time a patient hears the diagnosis of cancer, I don't believe they hear anything beyond that. The word "cancer" has a particularly severe psychological impact. Physicians have to stress that they really should look at it as a chronic disease and tell them the steps they have to take.

Participant

I was diagnosed a year ago, and I left the doctor's office feeling like it was totally up to me to do the research and figure out what to do. None of the doctors wanted to tell me what they thought I should do. I ended up contacting a friend who was a urologist and going from there. Somehow we need to get all of the information out to patients. From my perspective, there should have been more advice as to what a doctor thinks should be done in a particular case.

John Hairston, MD

The thing is that the whole process is overwhelming for patients, and that includes the amount of information that there is to sort through. I try to simplify it for patients, but ultimately every individual patient has to be comfortable with their decision. Prostate cancer is unlike any other solid organ tumor. As much as we would like to say, we don't know as much as we would like.

Participant

I would like to recommend that after a patient is diagnosed they should get their paperwork from their testing and see at least three different doctors from different disciplines to get a comprehensive perspective.

Participant

The concept of a database is great in terms of putting preferences in and having it spit out a solution, but at every step of the way there is a spectrum of decisions and treatments. Prostate cancer is unique in that the choice of treatment is guided a lot by personal preference. Decisions have to come from an active discussion about options and quality of life.