Transcript Details
This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: https://reachmd.com/programs/breaking-boundaries-breast-cancer/assessing-the-pros-of-patient-reported-outcomes-in-early-breast-cancer/11598/

ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Assessing the Pros of Patient-Reported Outcomes in Early Breast Cancer

Announcer:
Welcome to *Breaking Boundaries in Breast Cancer* on ReachMD, sponsored by Lilly. Here's your host, Dr. Charles Turck.

Dr. Turck:
Patient-reported outcomes are an effective way to measure the effects of a treatment, as well as a patient's overall quality of life. And while we may be familiar with reading about measures in clinical trials, it's worth asking: Might they also be applied directly in clinical practice to help us treat our patients with early breast cancer?

This is *Breaking Boundaries in Breast Cancer* on ReachMD. I'm Dr. Charles Turck, and joining me in this discussion is Dr. Lola Fayanju, Associate Professor of Surgery and Population Health Sciences at Duke University School of Medicine. Dr. Fayanju will also be leading a workshop focusing on patient-reported outcomes at the upcoming 2020 San Antonio Breast Cancer Symposium. Dr. Fayanju, welcome to the program.

Dr. Fayanju:
Thank you so much for having me.

Dr. Turck:
To start us off, Dr. Fayanju, could you tell us a bit about what patient-reported outcomes are and why they're used?

Dr. Fayanju:
Patient-reported outcomes are reports of health status, as well as overall quality of life reported by patients to their providers without any intermediary interpretation by the providers. It is a more direct way of understanding and assessing the patient experience, and perhaps also censoring our notions of what a good outcome is on the patient's perspective versus traditional metrics used by providers, such as recurrence or survival, that actually reflects higher level outcomes than maybe actually germanes the everyday lived experience of patients. And they're very important because we don't always understand why a patient may continue or stop a treatment, or why they don't make it to their appointments, or why they're not doing well on a particular regimen. And not infrequently, it's because patients don't want to "disappoint" their providers. And they may not want to actually say directly, "I hate the mouth sores this is giving me," or "I can't make it to the appointments because I can't afford the bus fare." So having a patient-reported outcome metric or an instrument to which patient-reported outcomes can be captured, allows patients to without direct confrontation with the physician or provider supply a sense of what their lives look like, and how their lives are interacting with their disease or treatment in order to provide a fuller sense of their overall experience.

Dr. Turck:
Got it. Now, if we were to zero in on their application in early breast cancer specifically, how might patient-reported outcomes help us care for that patient subgroup?

Dr. Fayanju:
There are a number of ways in which patient-reported outcomes can help patients, particularly when they're first being diagnosed with breast cancer. As you can imagine, the time after a woman finds out she has a new diagnosis of breast cancer can be an incredibly overwhelming and distressing period. And we want to make sure women are sufficiently motivated to pursue treatment without being so overwhelmed by the prospect of treating breast cancer that they regress away from contact with the medical establishment. There are a number of patient-reported outcomes we can use for when they are first diagnosed with breast cancer and no matter what their stage of

disease is.

One of them is the NCCN Distress Thermometer, which is used for all types of cancer types. And what this does is it assesses several different domains of a woman's kind of psychosocial health; namely, emotional, practical, physical, as well as spiritual, and logistical challenges that may affect their ability to engage with their care because they're causing so much distress. So, knowing where someone is and whether they might need help dealing with one of those domains of stressors contributing to their stress, can help us make sure patients get to care and continue care in a timely and appropriate fashion.

In addition, there are patient-reported outcome measures that can be used to guide women with regards to shared decision-making with their physicians. An example of that is the BREAST-Q. And what this allows women to do is compare their appearance of their breasts prior to any type of surgery with the outcomes after lumpectomy or mastectomy with or without reconstruction. And so, by engaging women with this type of patient-reported outcome measure, we're able to get a sense of women's baseline self-image, their kind of goals with regards to surgical treatment, and hopefully better understand the motivations behind why women might choose between two equally efficacious forms of surgery in their given circumstances and for their given reasons and motivations.

Women with breast cancer that is in early stage, the difficulties that there are actually a lot of choices in terms of what they could potentially do. And sometimes having a plethora of choices is overwhelming, and patient-reported outcomes can help them hone in on what is most appropriate for them.

Dr. Turck:
So then how could we go about incorporating these patient-reported outcomes into our clinical practice?

Dr. Fayanju:
The key to patient-reported outcomes being well received and well integrated is that, one, they need to be fairly simple and not particularly time-consuming either for the patient who is completing them, or for the clinician who might be entering this information into the medical record if it's not being entered directly by the patient. In addition, there needs to be a fairly clear way for that information to be interpreted and understood by the clinician. It shouldn't require another key to understand what the patient is saying and how it's being used to direct their care.

Another thing that's important ideally is that it's something that can be entered directly into the electronic health record. It diminishes the possibility of entry error, as well as the possibility of it not being entered at all. Also, it allows for timely intervention, such that if a patient immediately reports that they're having excessive pain, that's something that their clinician can immediately see and act upon, versus having a couple of steps between the symptom first being reported and it first being known to the clinician.

So there are a lot of opportunities for incorporating patient-reported outcomes into clinical practice. I recommend that anyone who's considered doing that, work with administrators in your electronic health record system as well as, if you have them, a patient-reported outcome governance or advisory board at your institution.

Dr. Turck:
Those are some excellent, excellent pointers. For those of you just tuning in, you're listening to *Breaking Boundaries in Breast Cancer* on ReachMD. I'm Dr. Charles Turck, and today I'm speaking with Dr. Lola Fayanju about the use of patient-reported outcomes in early breast cancer.

So, Dr. Fayanju, earlier you talked a bit about how patient-reported outcomes might be used in clinical practice, but if we were to switch gears a bit and focus on the research side of things, how could these outcomes improve the way clinical trials focusing on early breast cancer are conducted?

Dr. Fayanju:
So, one thing that we've learned through the use of patient-reported outcomes in the clinical trials is that there may be aspects of the treatment being received that will not be readily apparent or even anticipated by clinical investigators until they are reported by patients. And so, most clinical trial cooperative groups now have patient advocates who are members of the organization and help with providing a patient perspective with regards to how a trial should be conducted. And increasingly, cooperative groups are aware of the importance of incorporating patient-reported outcomes into trial design from its inception.

With regards to early stage breast cancers, I think where patient-reported outcomes are going to be really important in clinical trials is with regards to understanding choice, particularly with regard to de-escalation of treatment for types of breast cancer that we know are increasingly curable due to advents in systemic therapy and a recognition that not all treatments need to be the same for all patients.

So, as an example, the COMET trial is currently the only international trial examining whether or not women with low-grade early DCIS could potentially be spared from surgery and/or radiation that is local regional treatment if their DCIS is the kind of DCIS that is unlikely

to ever become a threat to a woman's life. And so, what we have in the case of DCIS, which is Stage 0, early stage breast cancer, in a situation where, for years, we've been treating that the way we treat someone with locally-advanced disease. Prior to the advent of sentinel lymph node biopsy, a woman with DCIS in her breast would get a mastectomy or lumpectomy and a lymph node dissection, and all the concomitant morbidity associated with that, including lymphedema, neuropathy, and decreased functional use of their arms. And so, to the extent that we can say, look, we now know that there are probably people for whom that was definitely overkill, and that it might even be overkill to do lumpectomy and radiation for a woman who has DCIS. Patient-reported outcomes can allow us to understand what matters to patients and how their priorities can inform their decisions as to whether to participate in the trial, but also outside of clinical trial practice, what they would do if given opportunities for choice with regards to how they treat their disease.

Dr. Turck:
Now, you touched on this a bit already, but I wanted to ask if there are any other ways patient-reported outcomes might be applied to research efforts around early breast cancer?

Dr. Fayanju:
I think another important opportunity for patient-reported outcomes to assist with regards to investigation is trying to understand how individually patient-reported outcomes can be extrapolated to an understanding of a population of individuals. In particular, can we look at how individuals respond on patient-reported outcome measures to understand whether there are particular groups of people who are at risk for either overtreatment on early stage breast cancer, or non-receipt of treatment for a cancer that really is entirely curable, and also to make sure that women are fully getting a sense of what their options are. One thing that we've learned in our study examining responses to the NCCN Distress Thermometer among women newly diagnosed with breast cancer that was published in *Cancer* is that there were big variations between different racial ethnic groups. And what we found is that Latina women had younger age at diagnosis, longer time to evaluation and time to treatment, but also higher rates of mastectomy without reconstruction, which would not imagine would be the first choice for young women diagnosed with breast cancer.

And so what that tells us as we look at the various things that contribute to distress at the time of diagnosis is that perhaps we are not engaging in appropriate shared decision-making with this population. We need to think about how to make sure that they know, are aware of, and fully take advantage of all the options for surgical management of breast cancer in 2020 in the United States. So, patient-reported outcomes allow us to understand not only individuals, but also populations potentially, and identify groups who might be at risk for desperate care and worse outcomes as a result.

Dr. Turck:
Now, lastly, Dr. Fayanju, let me open up the floor to you. Is there anything else you'd like to share with us about the application of patient-reported outcomes in early breast cancer?

Dr. Fayanju:
I think the most important thing people should think about is very thoughtful application introduction of these types of important indicators in their clinic. I really think that patient-reported outcome measures, when used thoughtfully and intervened upon, can really improve patient care. And this has been demonstrated in many studies.

Most importantly, patient-reported outcomes can't go into a vacuum. That is, if you're going to collect this data, you need to act on this data. And so, what I would recommend to individuals who are thinking about using patient-reported outcomes in their research or in their clinical practice is that you work with people in your electronic health record maintenance system in order to make sure that you are deploying patient-reported outcomes that are useful, that are easy to complete as well as to interpret, and that will actually lead to a change or intervention that is of benefit to the patient. Otherwise, we're simply wasting their time. But if we do this well, there's a real opportunity to better understand our patients as individuals, as well as in part of a larger whole.

Dr. Turck:
Well, this has been a fascinating look into how patient-reported outcomes can play a role in both the clinical care and research of early breast cancer. And I want to thank my guest, Dr. Lola Fayanju, for joining me in this discussion. Dr. Fayanju, it was great having you on the program

Dr. Fayanju:
Thank you again. It's been a pleasure.

Announcer:
You've been listening to *Breaking Boundaries in Breast Cancer*, sponsored by Lilly. To revisit any part of this discussion and to access other episodes in this series, visit ReachMD.com, where you can be part of the knowledge. Thanks for listening.