[MUSIC PLAYING]

**MARGARET QUINN ROSENZWEIG:** Hi. It's a pleasure to be here today. I want to thank Dr. Johnson and Dr. Nielsen for extending this invitation. I'd like to review financial toxicity and, as much as possible, try to relate this to the patient family with head and neck cancer.

I am the opening act for this discussion today. So there will be a panel after me trying to make this even more relevant to this specific population. I have no disclosures.

I'm very happy to see the issue of financial toxicity discussed in this forum. I came to my interest in financial distress among populations of patients through my research interest in racial and income cancer care treatment disparity. I'm particularly interested in the burden that financial distress places on vulnerable patient populations and, in particular, those with late stage cancers.

Defined by Carrera and Zafar in 2015, financial toxicity can be conceptualized as the unintended, but not necessarily unanticipated, objective financial response to cancer therapy. It is considered to be a toxicity of therapy, just as mucositis and neutropenia, and it is particularly related to the newer classes of drugs and newer concomitant health services.

This conceptual model of financial distress is presented by the National Cancer Institute. We can see a number of factors that influence, ultimately, patients and families with cancer experiencing financial distress. We start with the patient and family prior to illness and their comorbid financial situation. So that's their assets, their debts, the employment status.

And then, they encounter cancer of any kind of severity. And then, they have to consider their medical insurance. How will this cancer treatment be covered? The treatment choice is then influenced by the ability of the cancer to be covered through some type of insurance. And the deficit from that results in medical costs.

Along the way, there's non-medical costs that are occurring concomitantly because there's still the out-of-pocket expenses and other expenses just of incurring illness. That all can result, then, in financial strain and distress and can result in formal bankruptcy. Or it can result in poor health outcomes, as well as personal bankruptcy. And so these outcomes are all to be examined and considered in financial toxicity in cancer.

There was a wonderful review article by Altice and Yabroff in 2017 that looked at 676 studies that have addressed financial toxicity and cancer in the last 10 years. They only deemed 45 of these studies worthy of their review. And in that review, they looked, across the studies that were essentially cross-sectional, they looked at cancers of all types, often of all stages, and at any time during the treatment trajectory.

Although there was sort of this "mis-mush" of information here, they did find that of all these populations, or of all these samples, 49% of the patients reported some financial distress in cancer. 82% of the time, the researchers conceptualized this distress as material-- so what were patients paying? did they incur bankruptcy? those kinds of things-- where less often-- only about 15% of the time-- did they ask about psychological distress as a result of this financial toxicity.

62% of patients did incur some debt as the result of cancer treatment. And the really take-home message here is that 45% of patients said that they were not-adherent to some portion of their cancer treatment due to cost.

In an editorial, one of the thought leaders in the country, Dr. Zafar from Duke University, stated that we really need to now think beyond just the material aspects of financial toxicity and start to think about how is this impacting patients and their mortality? He put forth a hypothesis that there are three big factors that can impact the mortality of patients as a result of financial toxicity in cancer.

The first is subjective well-being. The patients who feel poorly about themselves may feel that their life isn't worth living, may be at higher risk for suicide, and may incur higher mortality in that way. Health-related quality of life is linked to greater risk of mortality in several cancer studies because of the additional physiologic distress that can occur.

But perhaps a more quantifiable and objective measure would be through this idea of quality of care, that if 45% of patients are not receiving dose intensity because of financial distress, we need to be concerned about that and that impact on mortality and cancer. He was really asking for us to move beyond descriptive research into interventional research.

There are many limitations to the descriptive work that's been done. While it has come forward and put this problem on the map, we are still looking at a lot of cross-sectional, cross-malignancy, cross-stages, and often not at the time of acute cancer treatment. Often, we're looking at years later, asking patients to recall both symptoms and the financial distress that occurred.

We're also looking at a lot of single-institution studies. And while that, in and of itself, isn't a bad thing, sometimes these institutions aren't necessarily low-resource areas. We now know the patients that are at highest risk for financial toxicity. And so we need to look at institutions that really have a greater proportion of these patients in order to better study this phenomenon.

And lastly, there are really not baseline measurements in many of these studies. And because of that, we're really not getting a pre- and what happens along the cancer continuum in terms of toxicity. But perhaps the biggest problem with these studies are the measurement issues.

So we have to ask ourselves, what are we measuring, how are we measuring it, and why are we measuring it? There are multiple financial outcomes-- material outcomes-- but we also have to look at the distress, the psychological distress, that can occur.

We have to think about significance. When we ask about trade-offs, when we say, did you not go on a family vacation because of financial toxicity? is that significant enough to get funders to say, yes, I'd like to fund this research or institutions to say, yes, I really want to put forth a program to help with financial toxicity? Perhaps we should be focusing more on what didn't you get in your cancer treatment? how is this impacting survival? as a more significant outcome.

And then, we also have to look at how practical are some of these measurement tools? A speaker spoke earlier about patients getting constant questionnaires put in front of them. We need to be smart about the tools that we're using.

There was a really great study that's reported for head and neck cancer in financial toxicity. And this, it looks like an internally funded study. But it is on clinicaltrials.gov. And this is called the PaRTNer Study. So this incorporates the things that aren't being done, for the most part, but now is kind of doing it right for head and neck cancer patients.

This PI, Yvonne Mowery, is going to look at head and neck cancer patients at baseline one, three, and six months after receiving radiation therapy, with or without chemotherapy-- so a very defined population, very defined time points for a very defined malignancy. She is looking at all measures of financial toxicity-- so financial distress and psychological well-being, quality of life-- and then looking at those outcomes of medication adherence and out-of-pocket expenses.

So this will be a true contribution to the head and neck financial toxicity literature. Because you really have a very specific study with very specific outcomes. So it truly is time for intervention.

We now know that there are high-risk groups that we can acknowledge and respond to. There is a great deal of patient heterogeneity in cancer. And there is also specific groups that we can target because we know that they are at higher risk for financial toxicity. So we can form these groups and begin to intervene in a more proactive manner.

If we look at a model of possible intervention, we look at, first, the pharmaceutical and government influences on cancer care and cancer cost. And then we look at the cancer care delivery system. Those are our givens. Then we have patients and families as they interact in cancer care, the financial toxicity distress and possible non-adherence, and then poverty, bankruptcy, possibly altered outcomes in survival.

And one of the ways that we can intervene is to do a more proactive assessment. And some of this can be done in a relatively simple fashion. We can send demographic questionnaires to patients ahead of time, ahead of their cancer treatment visit, and say oh, look at this patient. We know that they are in a specific group, and we can target them from the very beginning in order to prevent financial toxicity from occurring or to intervene early to prevent some of the distress with it.

Zafar, again, in a 2013 cross-sectional study, looked at 254 patients. This was a cross-sectional in a cancer institute, all comers. 75% of those patients applied for some type of financial assistance for drugs. He took that population, then, and said, among those patients, who's at highest risk for financial toxicity? And from that-- and many other studies have confirmed these findings-- we have a list of patients that we know are at greater risk.

So in his study, he found that there were patients that didn't have prescription drug coverage, that were younger, who actually had already communicated with their doctor about financial toxicity, single or not partnered, non-white race, patients with more advanced cancer who were more at risk. In our own study at Magee-Women's Hospital, we did a cross-sectional study of women with metastatic breast cancer to look at financial toxicity. And we divided the entire cohort of women who responded into high and low income.

And you can see here that the low-income and higher level income patients differed widely. The cost measurement is the measurement of financial toxicity. And there was a great deal of difference-- a significant difference-- in their financial distress.

Lower scores mean higher financial distress. And that correlated with their quality of life measured through the functional assessment of cancer therapy. And they had a significantly different quality of life. And this is throughout many studies, that there is a correlation between the quality of life and financial toxicity that's experienced.

So we know that not partnered, seeking assistance for financial help, advanced, more chronic disease, younger, and low-income patients are at higher risk. And we can intervene early with these patients. So that's one intervention.

The second intervention that we can do is screening along the way. So we might have patients that are at higher risk and get into those patients early. But then, we might have patients that incur financial distress and toxicity along the way. And for those patients, we can do some early intervention, navigation, education and counseling.

We have several tools that we can use for screening throughout the cancer treatment trajectory. And you're familiar with these tools. Comprehensive score for financial toxicity is the one that's now used in almost all research looking at financial toxicity and cancer. It's published by De Souza in 2014, validated in 2017, and is approved our patient reported outcome for financial toxicity.

The NCCN Distress Thermometer, which you're all familiar with, has been suggested to be put into practice and measures both material concerns, emotional concerns, and distress, or all three of those categories. Quality of life is mostly used in research investigations.

And there is a specific measure for head and neck cancer for quality of life. But it mostly measures emotional concerns and not very specific for financial concerns. And then, we can always ask patients about medication adjustment or do chart reviews for these kinds of issues.

This is a copy of the cost, what this looks like. And it has patients respond to questions about their financial anxiety. Lower scores are worse, and higher scores or better. So it goes from 0 to 44.

And then, this is the Distress Thermometer that you're all familiar with. And in the Distress Thermometer, patients can recount their level of distress and then specifically address which factor may be causing this distress. In many studies that have looked at the utilization of the Distress Thermometer, we see that the most often checked reasons for distress are the emotional concern category. Second to that, about 26% of patients will acknowledge that they are having some financial issues as a result of cancer therapy.

So that screening tool is fairly easy to use. And if financial distress is noted, you can use a navigation or financial counselor that may be available through your institution. It is important to know that financial counselors that are available through the institution are first obligated to get the institution paid for their medical bills, for the bills that the patient's incurring.

And so, while these counselors may be helpful to patients in other resources, sometimes they are not looking at the patient in a full, holistic manner. A navigator who is just assigned for financial reasons would be looking at the patient in a more holistic way, helping, of course, to get the bills paid but also to look at other factors.

Navigation has been a tried and true intervention in order to move patients across the cancer trajectory, and first brought to light by Harold Freeman in Harlem to get women with breast cancer more treatment-- into treatment-- but then has been used in many different aspects of cancer care very successfully. We have a navigation program in the breast center where I work. We review all of our metastatic breast cancer patients in the week prior to them coming to clinic.

And prior to the implementation of this program, we had about 13.5% of our patients referred for social work. And the great majority of the time, when patients are referred for social work, it was a navigation social worker who was seeing them for financial concerns. After the implementation of this program, we had 42.8% of our patients seeing social work within a period of three months.

And we calculated the cost of this. So for someone to review the charts and then to look out for possible specific areas of financial concern for the patient, to locate the social worker, and then to make sure that happens is about $750 a month.

And we now, a year into this program, have about 85% of our patients who have seen social work. And about 80% of those consults have been for financial reasons. So for that small amount of money, we've really been able to have patients have at least all of the access that they can have to financial resources.

Another implementation, or intervention, that can be done is reframing the financial distress. About 40% of patients will have financial distress or toxicity as a result of cancer therapy. But some 10% to 15% of these patients won't actually have material problems that result. They have a lot of anxiety about the possibility of the material problems that may result.

And so a reframing of the anxiety can help. Essentially, it's saying to patients, well, we can't pay your bills, but we might help you think a little bit differently about your bills in terms of the reframing that can occur. So it's an education and a way for patients to have some counseling about this might not be everything that you're worried about.

There was a pilot program that was tried for a financial navigator. And it was only 35 patients. But patients had access to financial education at the onset of their cancer diagnosis and treatment and then had a navigator along the way. And those patients had pretty high financial toxicity. 37% reported financial burden, and 47% anxiety about that. And their anxiety decreased, but the actual costs of their care didn't decrease, as the result of the financial navigation.

There's a lot of literature in the primary care literature about clinician counseling. And the numbers are really promising. Among 300 patients, 52% said they wanted to talk to their doctor about difficulty they were having in paying out of pocket for medications. Among the patients that did speak with their doctor, almost 60% of them did have lower out-of-pocket costs.

So we could say, wow, that's a really great intervention. Unfortunately, in cancer therapy, often, the therapy that's being discussed is the only therapy. It's not that I'm willing to pay a little bit more to have my drug twice a day instead of once a day or not the newest formulation of this antihypertensive med. This med in cancer therapy can be the most efficacious. And so these discussions, while promising in primary care, may not be as promising in cancer therapy.

ASCO is advocating for physicians to have that conversation with their patients. And they are strongly advocating for not only talking about cancer financial toxicity and cost but actually the benefit of therapy. They are working on a score that can be developed for adjuvant therapy and for later-stage therapy that calculates the benefit of the drug, the possible side effects of the drug, the cost of the drug to the patient. That would generate a score that is to be obtained by the oncologist. And then, that score is to be used in counseling with the patient.

For those of you who say, I'm not sure that that's really going to happen, it is a little bit idealistic. But ASCO is saying we can no longer just say-- physician, you can no longer say, I'm blind to the patient's financial issues. I'm going to prescribe this therapy. We really have to have a conversation with patients about the value to them of this therapy and what that is going to cost them, literally, in dollars. And so they are strong advocates for this and have put many resources towards this intervention.

And they are also asking-- through this process called Choosing Wisely that's been around for several years-- for oncologists to think about their practice and limit things that are not evidence-based and can save the patient money. When patients are asked to pay 20% copays on all of these things, we do have to think about everything that we recommend, and is there really evidence base, and is this necessary?

And so we do have information in order to decrease financial toxicity in cancer. We have demographic information. We have institutional programs that can be either instituted or brought to the patient. And we can work with providers to have more of a conversation with patients about financial toxicity.

We need to have large-scale, well-defined interventions. If we're going to now do interventional work, we have to have this with very high rigor so that we can build science from this. The interventions have to have the details of all of the intervention. We have to have a manual. We have to have how the personnel are trained. We have to have defined targets, dose of intervention, and very defined outcomes and measurement tools.

And lastly, as cancer care experts, we can advocate and really speak to those in pharmaceutical world and those in the government world about what this means for patients to have this anxiety about financial toxicity in cancer. We can work within our cancer care system to try to get affordable health care-- affordable cancer care-- for all so that from the front lines of cancer therapy, we can do what we can.

As citizens, we can speak to elected officials. As experts, we can do public advocacy. Institutionally, we can know our community and bring in experts to try to help patients who are struggling with financial toxicity.

And we can have cultural sensitivity and try to grow that within ourselves and our staffs about what it means to do these trade-offs of I have to feed my children, or I have to get medication. Because our patients are living with that, and we have to be sensitive to that as much as we can.

So we can start by doing what's necessary. It can move into what's possible. And who knows what we can accomplish by more of a sensitivity and awareness of financial toxicity in cancer? Thank you.

[APPLAUSE]