Ruth Adewuya, MD (host):

Hello, you are listening to Stanford Medcast, Stanford CME's podcast where we bring you insights from the world's leading physicians and scientists. This podcast is available on Apple Podcast, Amazon Music, Spotify, Google Podcast, and Stitcher. I am your host, Dr. Ruth Adewuya. This episode is part of our Hot Topics miniseries. Today, I will be chatting with Dr. Lidia Schapira on breast cancer and cancer survivorship.

Dr. Lidia Schapira is a medical oncologist focused on breast cancer and cancer survivorship. She completed her residency at the Beth Israel Deaconess Medical Center and did a fellowship in hematology oncology at the Brigham and Women's Hospital, followed by a research fellowship at Harvard's division on aging. With a passion for improving the lived experience of cancer patients and caregivers, she championed educational interventions to improve clinician and patient communication. Dr. Schapira's research and scholarship has contributed to advance our understanding of health outcomes for cancer survivors. She served as editor-in-chief for the patient education website of the American Society of Clinical Oncology and is currently an associate editor of the Journal of Clinical Oncology. Dr. Schapira, thank you so much for chatting with me today.

Lidia Schapira MD (guest speaker):

It's my pleasure. What an honor to be on your podcast.

Ruth Adewuya, MD (host):

As an oncology doctor specializing in breast cancer, what inspired you to focus on survivorship care? What are some unique challenges that breast cancer survivors encounter in their journey?

Lidia Schapira MD (guest speaker):

Through all of the decades of caring for patients, I've sat with so many of my patients and listened to them and perhaps helped them make important decisions about their life, their parenting, their kids, whether they were recently diagnosed or at the end of life, and there was so much about their life and their coping and how the experience of being a cancer patient was really impact their day-to-day life. That really resonated with me and struck me that I became very interested in thinking not only about partnering with enduring cancer treatment, but really helping them to think about life after cancer. So even very informally, before we even have this category of survivorship care, I would schedule time to have this life after cancer conversation with my patients and slowly really develop this deep interest in providing some guidance and understanding more through research about what that was like for them.

Ruth Adewuya, MD (host):

You're really on the forefront of this conversation in terms of what this life look after cancer, and it's exciting to hear that now it's more formalized research around it. It's incredible. Can you talk about some of those unique challenges that breast cancer survivors encounter in this journey that require that conversation to be initiated and to continue?

Lidia Schapira MD (guest speaker):

For breast cancer patients, mostly women, but of course there are a few men as well, although their stories are a little bit different, many of the conversations really begin with their bodies with sort of accepting the changes in body image and sometimes how they feel about themselves that will affect their relationship, will lead to thinking a little bit about how they see themselves, whether they're confident or not, whether they're confident walking on a beach in their new body and some of them have had quite extensive surgeries that really affect them. That's where this start.

And then with the use of systemic therapies, of course there may be an early menopause, and that's something that's very important for many young women who really live with bodies and challenges that normally they would face a decade or more later than their issues in relationships, issues in career building if they're parenting young children, how to think about that and the psychological impact of being treated for cancer, the trauma, the fears. We know through anecdotes, through practice and now through research that even fears and fears of cancer recurrence really impact the day-to-day life, often to distressing levels where really it intrudes in their ability to enjoy the day-to-day.

So there are a whole bunch of things to think about, how the exposures to cancer treatments may affect their future health risks, what they need to do to stay healthy. Maybe they have an accelerated cardiovascular risk or they have lost bone health as a result of treatments. So there are lots of pieces to pick up and put back into place.

Ruth Adewuya, MD (host):

What I'm hearing from you is that there are some long-term issues that survivors have to face. So when you enter the space, how do you approach the emotional and psychological aspects of cancer care for both patients and their caregivers, and why is it essential to address these aspects alongside medical treatment?

Lidia Schapira MD (guest speaker):

I think it is absolutely essential. A mental health is health, and if we just accept that, I think the way that we would think about cancer survivors and people undergoing active cancer treatment could change for the better. So that's one of the big messages I have for my colleagues, whether they're in general medicine or specialty practices or in the world of cancer medicine, I think the best thing to do is to make our visit safe places for people to just tell us what they're worried about.

And so beginning just by creating personal rapport, by identifying somebody on the cancer team who's available to listen to, somebody who is really needing to talk and perhaps even get some special mental health care. Some of these fears can be normalized and some of these issues are sort of part of being treated for cancer, but some really reflect a deeper emotional or psychological needs. So I think that it starts with just being open, just asking people how they feel, eliciting their concerns, getting a feeling for how severe some of these problems are, and connecting them with peers, with social workers, with mental health professionals, with support groups so that they can work through whatever it is that they need help or support with. Sometimes it can be guidance, sometimes it can be reassurance, but there are many more emotional needs that go unmet, and we know that. We know that from what we hear from patients and from research.

Ruth Adewuya, MD (host):

I really like how you framed your response to that question. You said start with creating the space, the safe space to have that conversation and then based off of what comes up, you can wrap around resources that are available. The other thing that you mentioned earlier is the fact that there is this increased recognition of the importance of these conversations and the importance of survivorship care plans for cancer survivors. Can you explain what a survivorship care plan entails and how it benefits patients in their long-term follow-up?

Lidia Schapira MD (guest speaker):

Absolutely. The survivor care plan concept came from the community of pediatric oncologists because they treat children with many drugs that will affect their growth, their future health. So that is the sector that developed and advanced the concept of having very comprehensive treatment summaries that detail the drugs, the radiation fields, the exposures, and provides very specific recommendations of what tests need to be done at regular intervals going forward to ensure the proper health and delivery of specialty services.

Now in the world of adult cancer patients, we've sort of adopted that concept and it was incorporated into an important report that was published in the year 2006 by the then Institute of Medicine, now the National Academy and now in the public domain and free, and I strongly encourage people to read it, which describe the fact that cancer survivors often felt lost in the transition between specialty oncology care and then back to primary care or community led care. So the idea in that report was that by creating a survivor care plan that detailed the exposures of treatment and provided an element of guidance, very specifically detailing what tests were needed and who would do that, that survivor care plan would serve to help that patient transition back, and they were supposed to send it to the primary care clinician and to the patient. Survivor care plans are considered tools that aid cancer survivors and connect the different professionals in the care team, mostly primary care with oncology care.

Ruth Adewuya, MD (host):

That sounds like the powerful tool for patients and frankly for clinicians as well. I wonder how pervasive is the utilization of this tool now? Is this a standard across institutions and health systems?

Lidia Schapira MD (guest speaker):

What started like a brilliant idea did not end up solving all the problems in practice. This was launched and promoted in the early aughts. Around 2006 it started, and then around 2018, 2019, there were some studies that at the implementation of these survivor care plans and aggregated the data and found that there wasn't a really convincing improvement in outcomes. Outcomes measured by survivors getting the proper care that this was something that cancer survivors said they liked and helped them, but that it wasn't really moving care in the direction that it had been intended to do and serve, and that the creation of these survivor care plans was laborious. So it was a lot of professional time and it really didn't convince the professional community that it was improving health outcomes for survivors.

And since then, in the last, say five years or so, the community has shifted perhaps to being less directed at creating those plans and more in thinking about how those plans could be simplified and using them as tools to guide what we think of as a survivorship visit, a visit that is focused on reviewing prior care, answering the patient's questions, coordinating their future care, identifying some unmet needs, and providing the necessary referrals. I think that if we look around the country, the implementation of these tools and the number of patients who receive it is probably under 20%. The ideal is that at least half the patients should get them, but the reality is that we're not quite there.

Ruth Adewuya, MD (host):

So it seems like there's still a lot more work to be done, but I think what's exciting about what I heard is that there's this recognition of the importance of the conversation, the discussion, and it's just a matter of, "How do we do it better and how do we actually make it happen".

Lidia Schapira MD (guest speaker):

I think that what excites me about this also is thinking about how we can use this concept to help patients manage their own healthcare, and that's just probably something that many others are thinking not just in the world of cancer care, but the idea of empowering our patients and cancer survivors to understand and be better prepared and more confident and more skilled, really at negotiating what we know is a fragmented healthcare system advocate for themselves and perhaps even teach some of their other clinicians about what it is that they need to stay and feel healthy.

Ruth Adewuya, MD (host):

As you have been working in this space and doing a lot of research and kind of education, what are some misconceptions or common myths about breast cancer or cancer survivorship that you frequently encounter and how do you typically address them?

Lidia Schapira MD (guest speaker):

Perhaps the more generalizable misconception is that patients or people are supposed to feel joy when they finish cancer treatment, and it's all about celebration, about ringing bells and having parties and taking trips and climbing mountains, and sometimes people feel really sad when they finish cancer treatment. There are people who undergo grueling treatments for months or even years and find themselves really at a very shaky place at the end. So the first misconception is that the journey is over with the last drop of treatment or the last pill, and it's really not. It continues. Other misconceptions are related perhaps to not understanding or having exaggerated ideas of toxic effects of treatments or somebody's own prognosis. I can't tell you how many breast cancer survivors I talk to who really feel that something terrible is going to happen, and when you sit with them and go over their prognosis, you see their facial expressions even change because perhaps they were more scared than they needed to be. So I think the misconceptions are often around how people feel, what their prognosis is, or even not fully understanding the effects of the treatments that they had.

Ruth Adewuya, MD (host):

I think this is very interesting. The first comment about how at the end of cancer care, the ringing of the bell, and I wonder if part of it is social media nowadays, you see a lot of videos, the ringing of the bell and then live happily ever after type thing, and I can imagine the pressure that a patient goes through if that is what people, the community around them expects.

Lidia Schapira MD (guest speaker):

I've had patients tell me that after their last radiation treatment, they just went in their car and they wept and they didn't feel that they could say it. They didn't know where to take this. So I'm very respectful of the fact that as one brilliant sociologist wrote years ago that we need to treat people who have just finished treatment for cancer almost as if they came from a special place or it had some advanced burn in the same way carefully not project perhaps what we think they should feel or what the expectation is. And that brings us to also talk about how we talk about cancer survivors or cancer patients or battling and winning, and I think there's a lot of pressure on being on the positive side and with those labels or with that language, we actually don't reach a whole lot of people who feel left out from that conversation.

Ruth Adewuya, MD (host):

That's very interesting. I wonder where the genesis of that approach and that terminology came from. I imagine for some it's helpful to think of it in that way, as you said, maybe for most it's not.

Lidia Schapira MD (guest speaker):

I can say in the world of the cancer professionals, a lot of this is based on the initial Richard Nixon talk about the war on cancer, and while I'm very happy with politicians pouring money into cancer research and please keep doing that, I do think that it's time to be more mature about how we think about people with cancer and people who live with advanced cancer and haven't failed. We haven't failed. It's just that something that at the moment we need to accept.

Ruth Adewuya, MD (host):

That's an excellent way of framing it, and I think it's a great segue to my next question to you around research. In your research and scholarship, what are some findings that you've seen that have contributed to better understanding of the needs and experiences of cancer survivors?

Lidia Schapira MD (guest speaker):

Thank you for asking that question. Some of the research I've done with many colleagues over the years have identified some of these trajectories for young cancer survivors, especially young women with breast cancer. In a study we published last year, for instance, in a cohort of young women with breast cancer that we followed for many years, we found that some, about a third had intense fear of cancer recurrence from the time they were diagnosed, and that did not improve over five years of follow-up.

Other findings are perhaps more positive, and that is that for the majority of cancer survivors, I would say time heals so that with time some of these things fall into place and that has to do with people's own abilities to cope with all of these wonderful psychological mechanisms that we put under the heading of resilience, that another positive outcome would be that we know, for instance, that families that go through cancer because a parent had cancer, that those kids develop resilience in their life so that if you're able to handle this well and promote open communication and model for the kids, the parent successful copings, that things are going to be fine and the kids are going to be all right.

So there's both research to show us that if properly handled, this actually can be resilience building, but also to show us that there's some individuals that are very traumatized and cannot resolve some of these issues just by themselves. Other research has to do with identifying, for instance, what we call late effects of cancer therapies, and that helps us to better understand what we need to look for not only in the immediate months and years that follow completion of cancer treatment, but recognize that perhaps 10 or 15 years later people can also be at risk for physical problems and those needs to be watched.

One of the very exciting areas I think, and that's not so much my research, but my colleague's research, is that by defining some of these late effects, we can then start to think about how we can prevent them. So one good example in the survivorship field for instance, is the emergence of cardio-oncology as a specialty. We recognize that some cancer treatments can affect cardiovascular health and risk. We identify people who are at risk and we can refer them earlier for preventative cardio-oncology advice and consultations. If we know what cancer survivors are at risk for, perhaps we can intervene early.

Ruth Adewuya, MD (host):

I love how there's constant evolution and breakthroughs that are happening in this space to better support our patients. Your work also involved making cancer information accessible to the general public. You previously served as the editor in chief of cancer.net. How do you ensure that high quality information about cancer reaches the lay public?

Lidia Schapira MD (guest speaker):

This is a topic that's dear to my heart. After six years, I passed the baton on to my wonderful colleague, Jyoti Patel. But for the six years that I held that position, I was really privileged to work with a team of staff, writers and educators, and really think about how to make expert vetted quality information more accessible to people around the world. And cancer.net is the website for a professional society, the American Society of Clinical Oncology. So it is a site that is intentionally free of commercial input. It's really directed to distill the information from volunteers who are experts throughout the country and throughout the world that we call on to tell us what's important and then have that information put in such a way that it's easy to access.

We've worked with focus groups, we've worked with experts to try to think about people who have different needs and make the information more accessible both in the way we present it visually and making it available to people who are hearing impaired, who are visually impaired so that they can also access it. And we tried as much as possible to make the information relatable and interesting and certainly keep it updated.

Ruth Adewuya, MD (host):

Amazing resource that people need to be aware of, cancer.net. In your past role and as you've led a charge in making sure that it was accessible, what were some of the biggest barriers to information accessibility that you found? I could see you having a specific lens in that role, so I'm curious about your thoughts there.

Lidia Schapira MD (guest speaker):

I really appreciate the question. I've obsessed about all of these things time and again. I always thought about people with low literacy, people who had a preference for language other than English. I thought about people who may read what we recommend but not have access to those services, and those were the kinds of things that sort of kept me up. How do we use this incredible medium to really help people get the best possible care wherever they're at? Dear to my heart was the issue of translation. So during my tenure, I certainly made it a requirement that all the new material that was created was translated into Spanish since that is an important language for people both in the US and worldwide. And the other was we talk about access is to expand the content itself to cover not only the specifics of cancer treatment, but also quality of life and how to live with and beyond cancer.

So we added more content on coping, on families, on survivorship, on end of life care, on communication, and really expanded what we were talking about and what we were writing about. And the final comment is that we were very open trying to create content that responded to the needs of the people who wrote to us and did our best to really listen across the country to what people thought was most important. There are cancer types that have huge advocacy groups already. So the breast cancer community that I am part of has so many wonderful organizations that are already thinking about it that are not really where cancer.net focused mostly on. We really took some of the cancers that needed that information to be created and brought to the public. So that's how we dealt with access. We were constantly thinking about who we wanted to reach, who needed us, and how we could ultimately reach the people who were living with these diseases and indirectly even train their clinicians.

Ruth Adewuya, MD (host):

That's incredible. What I heard is that this multifaceted approach to really considering how best to reach the people that need it and really democratizing that knowledge and what a powerful tool for patients.

Thank you for sharing that. As we wrap up our conversation and looking into the future, what are the key areas of focus or improvements in breast cancer care and survivorship?

Lidia Schapira MD (guest speaker):

Unpacking what breast cancer into different biologically driven subtypes, I think that's really made a huge difference. So understanding the differences, understanding what is making cancers grow, and then targeting our interventions and our treatments to really be much more specific. There's been, for instance, great advances in a particular subtype of cancer driven by the oncogene HER2. If we look at the last 25 years, we've gone from being able to treat advanced disease to preventing recurrences, to completely changing the prognosis for patients living with this particularly aggressive form of cancer that also is very amenable to treatment. Another great advance I think, in breast cancer that totally affects survivorship is that we've realized that we don't need to give toxic treatments like chemotherapy to a large number of patients that were previously receiving it by really understanding more about the prognosis of those cancers. So we now use some genomic profiles that are widely available at the time of diagnosis, and with that these days, we're able to avoid giving chemotherapy, for instance, to a large number of women. To me, that's progress. Deescalating cancer treatment is certainly one big advance for survivorship.

Ruth Adewuya, MD (host):

It may be surprising for our audience to hear from an oncologist to talk about reducing the amount of chemotherapy, but I think that's really powerful because ultimately if we circle back to where we started this conversation about the impacts of all of these long-term treatments on the patient into the future, that certainly is a good reason to ensure that we are looking at ways to reduce the amount of that kind of toxic treatment for patients. Thank you so much for chatting with me today on this topic. It gave us this insight into the part of cancer that maybe is not spoken about generally. So thank you so much for sharing your insights with us today.

Lidia Schapira MD (guest speaker):

You're so welcome.

Ruth Adewuya, MD (host):

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