WNPR Radio Voice 00:00:00:02 - 00:00:32:15 Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital. Welcome to Yale Cancer Answers with the director of the Yale Cancer Center, Dr. Eric Winer. Yale Cancer Answers features conversations with oncologists and specialists who are on the forefront of the battle to fight cancer. Here's Dr. Winer. Dr. Winer October is Breast Cancer Awareness Month, and during this month, we recognize the ongoing challenges and very substantial breakthroughs in breast cancer care. Tonight on Yale Cancer Answers, we're focusing on what can be an overlooked aspect of cancer care, and that is the financial challenges that many patients face during their treatment, which can potentially limit some of the progress that we've made. Our guest is Dr. Rachel Greenup, who is the Chief of Breast Surgery at Yale School of Medicine in the Department of Surgery. She is a professor of surgery and a leader in breast cancer research. Her recent work, which is funded by our federal government, is focused on financial toxicity, and she will describe more about that. Rachel is passionate about supporting patients with economic challenges, particularly when these challenges affect our ability to provide optimal care. Rachel, thanks so much for being here with us tonight. Dr. Greenup 00:01:32:27 - 00:01:35:26 Thanks for having me, Eric. Dr. Winer 00:01:35:26 - 00:02:03:26 So, you know, I always like to start with a little bit of background. What brought you to this field? What led you to become a surgeon and, in particular, a breast surgeon? Dr. Greenup 00:02:03:26 - 00:02:48:02 I was raised by two physicians—two academic physicians. My mother was an academic nephrologist, and my late father was an academic transplant surgeon. They loved their work. People often ask me if I was pressured to become a doctor, and the answer is no. I saw how happy they were and how fulfilled they were in caring for others, and it was really contagious. I swore I would never become a surgeon like my father, but when I got into the operating room, I got bit by the bug. Breast cancer surgery is a really unique opportunity to have long-term relationships with patients and their families, to help them at a really scary time, to make critical decisions, to remove their disease, and then to see them healthy on the other side again. I can't think of many professions that provide that incredible relationship or the ability to serve people in such a deep way. Dr. Winer 00:02:48:02 - 00:03:23:07 I feel similarly. It is truly a very rewarding field. Let's jump right into financial toxicity. It's a term that I think many of our listeners might not be incredibly familiar with. I think they can probably figure out, in one way or another, what it means. But tell us how you would define financial toxicity. Dr. Greenup 00:03:23:07 - 00:04:24:09 The term "financial toxicity" was first introduced into the medical literature in 2013 by my colleague and friend Dr. Yousuf Zafar, who was on the faculty in medical oncology at Duke University at that time. It was introduced to describe the severe financial strain and emotional stress that patients and families experience when going through cancer treatment. As doctors, we recognize the physical side effects of cancer treatment—things like numbness, hair loss, or scars after surgery. But we weren't acknowledging the financial side effects of a major medical illness. Medical illness is still the leading cause of bankruptcy in the United States. Bringing the term "financial toxicity" to the forefront gave patients, families,

and both academic and community oncologists an opportunity to come together to study and begin addressing this issue. Dr. Winer 00:04:24:27 - 00:05:01:25 And it's not just a matter of not being able to pay a bill. It's all the emotional angst that can come with that, which can range from mild anxiety to real depression at times. I mean, I can tell you as someone who can pay my bills, when I get bills from the hospital or from various places, I still look at them and say, "I thought I already met my deductible!" There seems to be this endless bureaucracy around it. So for someone who's well-off, it's anxiety-provoking, let alone for someone who doesn't have resources. Dr. Greenup 00:05:01:25 - 00:06:10:16 That's absolutely correct. There are different categories of financial toxicity, also known as financial hardship. First, there are the direct costs, which are the bills to pay for medical treatment. Then there are indirect costs, which are missed opportunities to earn money because patients are taking time off work to receive treatment. People who have been diagnosed with cancer know that receiving treatment—being in the hospital, waiting for chemotherapy infusions—is practically a full-time job. Finally, there are hidden costs that we don't always address as much: things like wigs for chemotherapy-related hair loss, post-mastectomy bras, physical therapy appointments, bandages for wounds, gas for trips to the hospital, parking costs, and more. All these things add up over time. Dr. Winer 00:06:10:16 - 00:06:52:22 It adds up hugely. And don't forget all the meals that you might buy while waiting for your visits, meals you'd otherwise eat at home. And it often doesn't just involve the patient—it might involve a family member or a friend who's helping them. That person might also have to take time off work or use personal days, which adds to the financial strain.

Dr. Winer 00:06:52:22 - 00:07:35:14 So, how common is this problem? I mean, in a sense, you can imagine it affects everyone to some degree, but in terms of causing real distress or interfering with care, are there estimates about how frequently that occurs? Dr. Greenup 00:07:36:12 - 00:09:00:15 Yes, and it's a great question. Initially, financial toxicity was described as a quality-of-life issue, which it certainly is. The literature reports that 50% to upwards of 75% of individuals with cancer experience some form of financial hardship related to their diagnosis. About 40% of insured individuals report difficulty paying for their deductibles, and about 25% report having to tap into savings to pay for care. A landmark study by Scott Ramsey, published in 2013, was critical in getting people's attention. It showed a clear risk of mortality when patients faced bankruptcy after a cancer diagnosis. The stress of being unable to afford bills can actually reduce longevity or survival following cancer treatment. There's also compelling data showing that when people can't afford their care, they skip treatments. For example, even a $30 monthly co-pay for Tamoxifen or endocrine therapy can deter women from filling their prescriptions for a drug we know is lifesaving for breast cancer. Dr. Winer 00:09:00:15 - 00:09:33:08 It's been said that it makes absolutely no sense to have co-pays for drugs that improve survival because the costs to society of premature death are enormous—not to mention the individual and familial costs. Co-pays are just such a deterrent.

It's incredible. So, can you count on patients telling you about these financial challenges? Dr. Greenup 00:09:34:04 - 00:10:43:24 This is something I've looked at extensively in my work, and the data is very clear—there remains a stigma and shame associated with asking for financial support. What happens in reality is that some patients recognize early on that they'll struggle to pay for care, and they are either identified by the health system or they proactively ask for resources. On the other end of the spectrum are individuals who have no financial concerns. But for the majority of people, they either don't realize they have financial issues, or the health system fails to identify them as being at risk. Most people don't reach out for help until they're in crisis. One of our social workers recently shared a story of a patient who called her only after accumulating $100,000 of debt related to their cancer diagnosis. My goal with my research is to remove the stigma of asking for help and to ensure that all patients are made aware of the resources available to them, both within and outside of the health system. Dr. Winer 00:10:44:11 - 00:11:16:13 The other day, I was talking to someone involved with the Tommy Fund, which raises money for pediatric cancer patients. He described a family whose refrigerator stopped working, and they were trying to store medicine for their child that needed refrigeration. What the Tommy Fund did was bring a refrigerator to the family's house. But not everyone has access to organizations or connections like that. Dr. Greenup 00:11:16:13 - 00:12:34:26 That's right, and it's heartbreaking. Pediatric cancer cases are, in some ways, even more pressing because a parent, who might be the wage earner, often has to be ever-present with their child. There's also the need to travel for care, which adds to the burden. Another issue is that patients might feel ashamed to admit they can't pay their bills, or they might not want to "waste" their doctor's time. They want to focus on discussing their surgery, their wound healing, or their next steps in treatment. There's a fear that talking about financial challenges will somehow detract from their medical care. Dr. Winer 00:12:34:26 - 00:13:39:16 Yes, and many patients feel rushed during their appointments. And unfortunately, many physicians—whether due to time constraints or other reasons—rush patients through those appointments. The key message we need to send to patients and families is that we're here to take care of the whole person. We have a team behind us to do that. If patients don't want to use their time with their doctor to talk about financial or non-cancer-related issues, we have extraordinary social workers, psycho-oncologists, case managers, and financial navigators who can help support them in other areas of their lives. Dr. Greenup 00:13:40:00 - 00:14:13:01 Absolutely, and there are also great nonprofit organizations out there. For example, Infinite Strength is a group that provides direct support to women with metastatic breast cancer who are single moms. But you're right—while that's a wonderful resource, it's still a relatively niche area. We need resources for everyone. Dr. Winer 00:14:13:10 - 00:15:16:13 We're going to take a brief break, but when we come back, we'll continue our conversation with Dr. Rachel Greenup, a professor of surgery at Yale School of Medicine.

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cer Hospital, where nationally renowned breast cancer specialists deliver compassionate, cutting-edge care. Learn more about innovative treatment options at SmilowCancerHospital.org. There are over 16.9 million cancer survivors in the U.S. and over 240,000 here in Connecticut. Completing treatment for cancer is a very exciting milestone, but cancer and its treatment can be a life-changing experience. The return to normal activities and relationships may be difficult, and cancer survivors may face other long-term side effects of cancer, including heart problems, osteoporosis, fertility issues, and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers like Yale Cancer Center and Smilow Cancer Hospital. The Smilow Cancer Hospital Survivorship Clinic focuses on providing guidance and direction to empower survivors to maximize their health, quality of life, and longevity. More information is available at YaleCancerCenter.org. Dr. Winer 00:15:46:05 - 00:16:19:14 Good evening again, and welcome back to the second half of Yale Cancer Answers. I'm Dr. Eric Winer, and tonight we're discussing the financial toxicities and challenges associated with breast cancer treatment—and more generally, cancer treatment. I've been speaking with Dr. Rachel Greenup, a professor of surgery at Yale School of Medicine, who has conducted and is conducting research in this area of financial hardship. Rachel, maybe we can talk a little bit about some of the research you're involved in and some of the early findings. Tell us a little bit about what you do. Dr. Greenup 00:16:20:04 - 00:18:12:26 I've been studying financial toxicity now for almost ten years. I describe myself as a mixed-methods health services researcher. My aim is to improve health equity through high-value care and to provide "just-right treatment" for the patients in front of us while preserving resources for the cancer population as a whole. My early work focused on understanding how women make decisions about surgery and whether financial impact informs their choices. We found that many women are thinking about cost, but they're not talking to their medical team about it. For women who are extremely impoverished—those making below the poverty level, less than $35,000 per year—financial security was often a higher priority than even keeping their breast. We spend a lot of time talking about the cosmetics of breast surgery—where the scars will be, what the reconstruction will look like—but for many women, keeping food on the table is their primary concern. We also found that choosing a double mastectomy, which has become increasingly common in the U.S. over the past two decades, is associated with a higher risk of financial toxicity. It's also linked to greater employment disruption. The time it takes to recover from the surgery often pulls women out of work, meaning they earn less money and miss professional opportunities. Some women reported paying upwards of $45,000 out of pocket for their care. They took out second mortgages, borrowed from friends and family, and told us that no one on their healthcare team talked to them about the financial impact of these decisions. The unexpected financial burden made it very difficult for them to plan. Women have told us that they want to understand not just the medical aspects of their care, but also how cancer will affect their lives as a whole. Unfortunately, as a healthcare system, we're often reactive rather than proactive in addressing these concerns.

Dr. Winer 00:18:13:12 - 00:19:19:22 That's incredibly important work. And I think it's worth emphasizing that the choice of bilateral mastectomy—removing both breasts—has been a growing trend for women with cancer in one breast. This is often done not for medical reasons, but for peace of mind or symmetry with reconstruction. For the audience, the data is very clear: removing a healthy breast does not help women live longer. It can reduce the risk of a second breast cancer, but for many women, that risk is already very low. If another cancer were to occur, we're typically able to detect and treat it early. That said, we want women to make the decisions that feel best for them. But we also need to ensure they understand the potential financial consequences of those decisions. Dr. Greenup 00:19:20:00 - 00:21:29:19 Exactly. The controversy around double mastectomies is primarily about women with cancer in one breast who choose to remove the healthy breast. The rate of double mastectomy in young women has increased by over 30% in the past decade. Many young women choose this option for peace of mind, symmetry with reconstruction, or to avoid the trauma of hearing "you have cancer" again. These are all valid reasons, but it's important to have a full conversation about the potential financial and personal impacts. For example, double mastectomies often result in more numbness and body image concerns than women initially anticipate. Women have told me, years later, that they didn't fully understand what they were getting into. This is why I believe that talking about financial security as part of the decision-making process is critical. Dr. Winer 00:21:29:19 - 00:22:04:06 Yes, and I think we all share the goal of ensuring patients make decisions that are truly informed and aligned with their values. But that can be challenging in the emotionally charged weeks or months following a diagnosis. It's easy for patients to make knee-jerk decisions during that time. Anyway, I want to return to your research on financial toxicity. Tell us about the present work you're doing. Dr. Greenup 00:22:04:07 - 00:24:03:28 Like all good science, our current work has evolved from trial and error—learning what works and what doesn't. When we realized that finances were a significant part of women's surgical decisions but weren't being addressed, we initially tried providing cost estimates, financial navigation, and educational materials about deductibles and co-payments. But we found that at the time of diagnosis, women are so understandably overwhelmed that they can't process this information in a meaningful way. So we shifted gears and started exploring storytelling. We wanted to see if hearing from other women who had experienced financial toxicity could be a more impactful way to educate patients. The Forecast Study was a beautiful collaboration between myself, Dr. Lee Pusztai, Matthew Dicks (a storytelling expert from West Hartford, Connecticut), and JH Artistry (a videographer from Fairfield, Connecticut). We recruited young women who self-reported financial toxicity to participate in two storytelling workshops. They then shared their experiences in a storytelling slam, which was profound and well-attended. We also video-recorded a subset of these women to share their stories through video. Our goal is to test this approach in clinical settings to reduce the stigma around financial toxicity, open the door for conversations, and provide early support from social workers and nonprofit organizations. Dr. Winer 00:24:03:28 - 00:25:14:09 That's such

a fascinating approach—using storytelling to connect with patients and break down barriers. Financial toxicity is such a big problem, and as you said earlier, we're really just beginning to scratch the surface. In our healthcare system, we often provide the very best care, but there are also situations where care isn't as good—either because people don't have access or, as we've been discussing, because financial concerns prevent them from seeking care. Are there specific groups of people who are at higher risk of financial toxicity or of avoiding care altogether? Dr. Greenup 00:25:14:20 - 00:26:26:14 Yes, the data is clear. Individuals under 65—those of working age who aren't eligible for Medicare—are at higher risk of financial toxicity. Within that group, women and minority women are particularly vulnerable. People with hourly wage jobs, who don't have employer-based insurance or reliable salaries, are also at high risk. These are individuals who can't afford to take time off work because if they don't work, they don't get paid. We also know that if you're paying more than 30% of your household income toward medical bills, you're at very high risk of financial toxicity. Dr. Greenup 00:26:26:14 - 00:27:26:21 Programs like Medicaid are critical for providing support to individuals at the greatest risk. Additionally, nonprofit organizations, such as Infinite Strength and national groups like the Patient Advocate Foundation, can provide financial assistance and case management for individuals going through cancer treatment. Dr. Winer 00:27:26:21 - 00:28:08:05 And of course, as I think everyone is aware, there's some amount of waste and unnecessary testing in all of healthcare. Wouldn't it be amazing if we could eliminate those unnecessary tests and instead direct those dollars to support the people who truly need it? Dr. Greenup 00:28:08:05 - 00:28:35:05 Absolutely. We waste more in healthcare every year than we spend on educating our children in the public school system. It's staggering. About a third of the waste is related to administrative complexity. Another 25% is related to inaccurate pricing, and 20% is due to poor care coordination and low-value care—essentially, over-treating people for reasons that aren't entirely clear. About 10% of waste is due to outright fraud, and the remaining 20% is from failing to deliver the right care at the right time. Dr. Winer 00:28:35:20 - 00:28:55:19 It's extraordinary to think about the amount of waste in our system. If we could redirect even a fraction of those resources, we could make such a difference for patients facing financial toxicity. Dr. Rachel Greenup is a professor of surgical oncology at the Yale School of Medicine. If you have questions, you can email us at CancerAnswers@Yale.edu. Past editions of the program are available in audio and written form at YaleCancerCenter.org. We hope you'll join us next time to learn more about the fight against cancer. WNPR Radio Voice Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital.