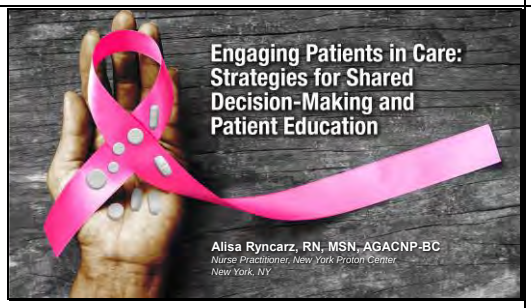
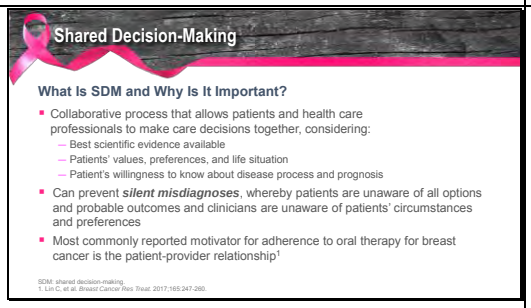
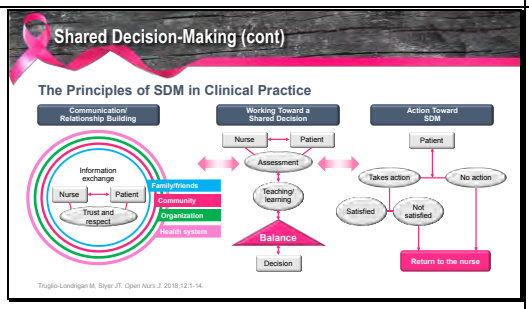
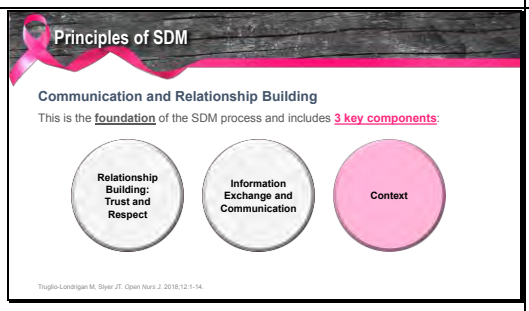
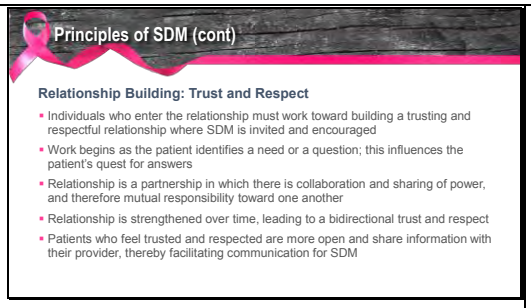
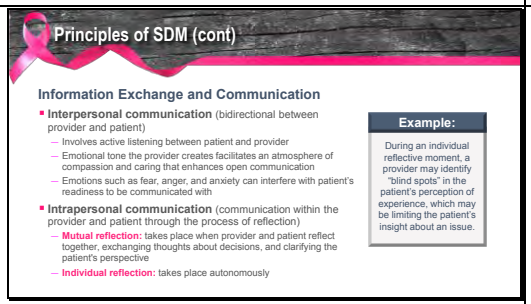
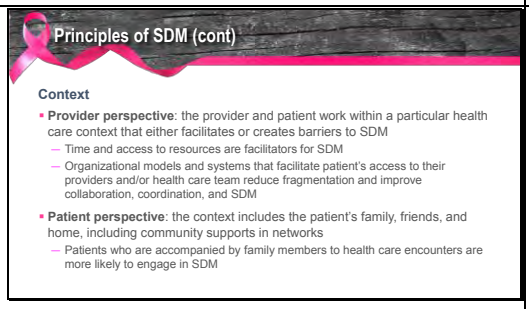
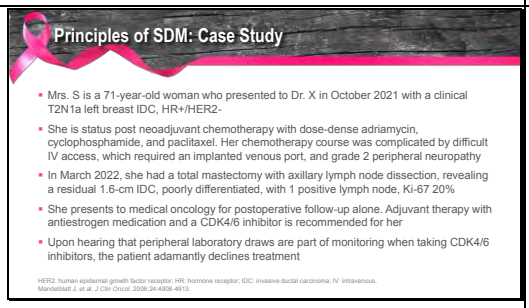
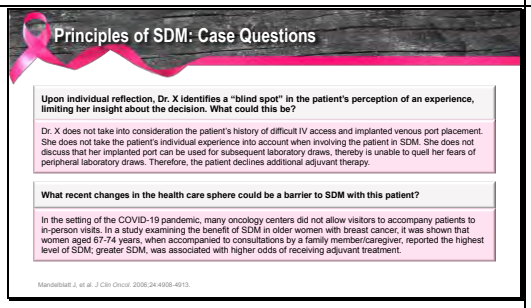
1		My name is Alisa Ryncarz. I am an oncology nurse practitioner in New York City. And today's activity that we'll be discussing is "Engaging Patients in Care: Strategies for Shared Decision-making and Patient Education."
2		
3		What is shared decision-making, and why is it important? Shared decision-making is a collaborative process that allows patients and healthcare professionals to make care decisions together, considering the best scientific evidence available, the patient's values, preferences and life situation, and the patient's willingness to know about the disease process and prognosis. This is important, especially in the healthcare context of early-breast cancer patients because it can be very important in preventing silent misdiagnoses where patients are unaware of all options and probable outcomes, and clinicians are unaware of patients' circumstances and preferences. The most reported motivator for adherence to oral therapy for breast cancer patients is the patient/provider relationship. And we'll see as we move through to discuss shared decision-

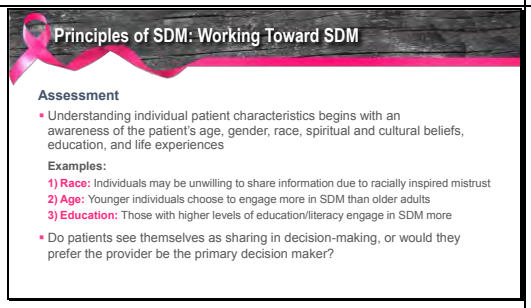
		making, the patient/provider relationship is integral to this.
4		The principles of shared decision-making in clinical practice. Basically, there are 3 steps that we look at. First is communication and relationship building, and we will go into these in greater detail. The second is the actual action of working toward that shared decision, what communication is had between the patient and the provider. And the third is the action that is taken by the patient, or not taken by the patient, and what happens after that decision point.
5		The first principle that we'll discuss is communication and relationship building. This is the foundation of the shared decision-making process and includes 3 key components: Number 1 is building trust and respect between the nurse and the patient or the provider and the patient. Number 2 is the actual information exchange and communication that is had between the 2 parties. And number 3 is the context, the context that the patient and the provider take into this conversation and decision-making process.

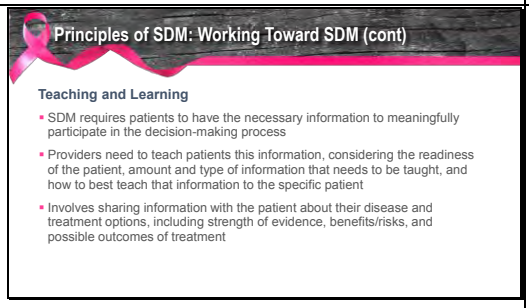
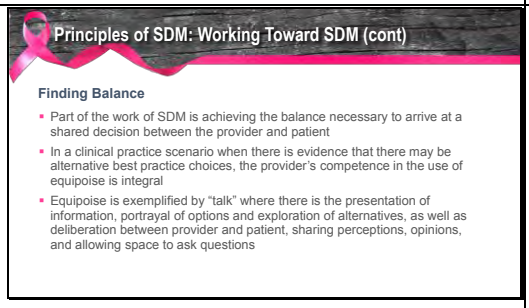
6		Trust and respect. For those of you who are in clinical practice, I'm sure you've experienced that this is something that's very important and something that can impact all aspects of a patient's care, including their overall experience as they move through their cancer journey. But specifically, when it comes to making shared decisions about treatment, we know that trust and respect between the patient and the provider are very, very important. We want to make sure that there's collaboration and sharing of power and a mutual responsibility toward one another. We know that this relationship isn't something that initially starts out absolutely fully grown. It's something that's strengthened over time as these patients move through their cancer journey, from chemotherapy, to surgery, to radiation, to adjuvant therapy. We know compassionate trust and respect is something that is earned, and we know that patients who feel trusted and respected are more open to share their own information and their own thoughts and feelings with the provider, which facilitates communication for shared decision-making.
7		When we talk about the next step, information exchange and communication, there are 2 different subtypes of this: The first is interpersonal communication. That's the communication that happens between the provider and the patient, and the second is intrapersonal communication. And what that is, either

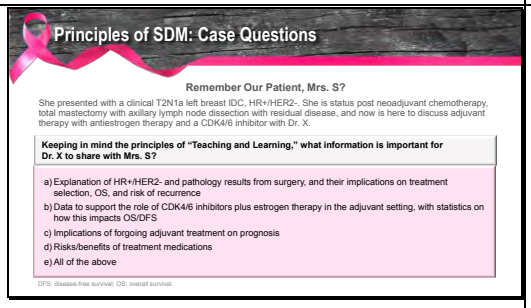
		with the provider and patient together or each of those individually, their own reflection of how the decision-making process is going. So interpersonal communication involves active listening between patient and provider. What is important is the emotional tone. That creates an atmosphere of compassion and caring that enhances open communication. And we know that emotions between the provider and the patient such as fear, anger, and anxiety can interfere with the patient's readiness to be communicated with about a certain decision. When we look at the intrapersonal communication specifically, there is either a period of mutual reflection where the provider and patient reflect together, exchanging thoughts about decisions and clarifying the patient's perspective on why they made a certain decision. And then there's also individual reflection, which takes place autonomously. An example of this is the provider can sometimes identify a blind spot in the patient's perception which may be limiting the patient's insight about an issue, and that's something that would be found during individual reflection.
8		The third step in the principles of shared decision-making when it comes to involving this in clinical practice is taking in the context of both the provider and the patient. For the provider—and as providers we know that things like stress, access to resources and time specifically, all of those aspects of organizational systems that we operate within—those can all influence

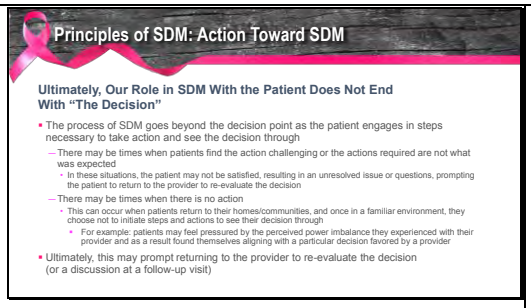
		our ability to have these long and thorough discussions with patients. And the patients, they're coming in with their context—be it their family, friends, previous experiences, community, support groups, religion—all of those things are kind of preparing the patient for a context and they're bringing up how they're going to respond to these discussions. And one of the things that we know is that patients who are accompanied by family members who bring some of that context into the decision itself are more likely to engage in the shared decision-making, which ultimately helps with things like medication adherence.
9		We're going to talk about a case study. This is a patient, Mrs. S. She's a 71-year-old woman who presented to Dr. X in October of 2021, with a clinical T2N1a left breast invasive ductal carcinoma, hormone receptor-positive/HER2-negative. She is status post-neoadjuvant chemotherapy with dose-dense ACT. Her chemotherapy course was complicated by difficult IV access, which required an implanted port, and grade 2 peripheral neuropathy. In March of 2022, she had her breast surgery. She had a total mastectomy with axillary lymph node dissection, and this revealed a 1.6-cm invasive ductal carcinoma, poorly differentiated, with 1 positive lymph node, a Ki-67 of 20%. She presents to her medical oncologist, Dr. X, again for a postoperative follow-up. At this meeting, an adjuvant therapy regimen was discussed, including antiestrogen medication and a CDK4/6 inhibitor.

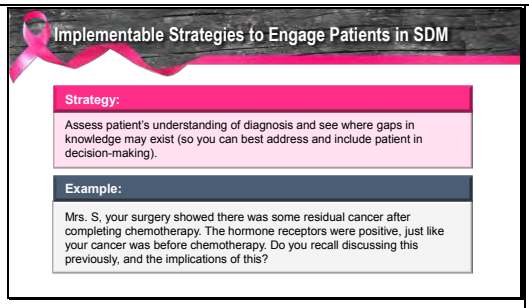
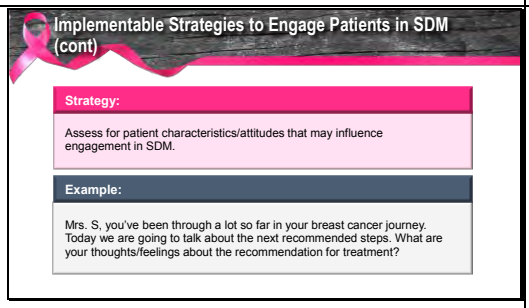
		Upon hearing that peripheral lab draws are part of monitoring with this medication, the addition of the CDK4/6 inhibitor, the patient adamantly declines this treatment.
10		Upon individual reflection, Dr. X identifies a blind spot in the patient's perception of an experience. What could this be? She does not take into consideration the patient's history of difficult IV access and the fact that she needed a port during treatment. Without taking the patient's individual perspective and individual experience through the pre-adjuvant therapy discussion, she's not allowing the patient to be reassured in a way that would ultimately help her make this decision. In this case, if the provider had known or thought about the patient's specific experience, she would know that we could do these lab draws through the port, which would assuage the anxiety that the patient's having about taking this additional medication and additional lab draws, and hopefully would help convince them to make the recommended decision of taking this extra adjuvant therapy. Also, when we talk about specific healthcare context involved in the shared decision-making and how it can make a difference, we can look at what recent changes in the healthcare sphere are a barrier to shared decision-making. What we know is that since the COVID pandemic, a lot of oncology centers haven't allowed visitors. By not having visitors or not having actual community support or family support when patients are undergoing these decisions, they sometimes do not feel that they're

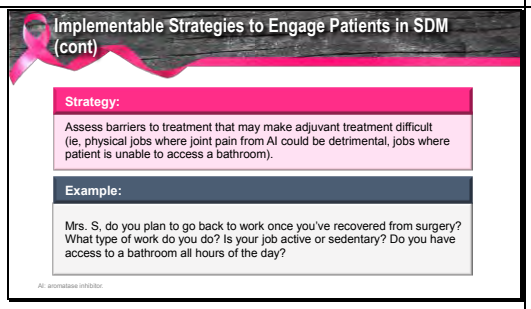
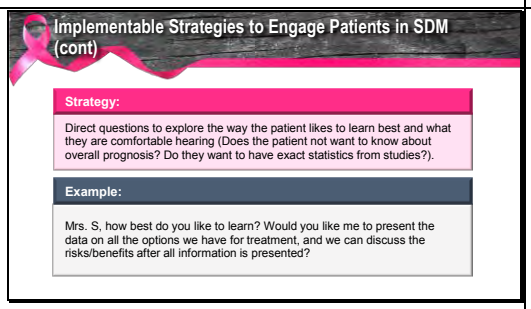
		empowered to make the decisions that they want to. We've seen specifically in my own personal practice during the COVID-19 pandemic that sometimes these patients who are at these conversations by themselves are not taking the full situation into account when they are saying no to a certain adjuvant therapy. There's actually been studies that have shown that when accompanied to consultations by a family member or caregiver, there's a higher level of shared decision-making, which is associated with higher odds of receiving adjuvant treatment.
11		The next step of the shared decision-making process is really this area where we're working toward shared decision-making. And the first aspect of this is assessment. And that is understanding an individual patient's characteristics with an awareness of the age, gender, race, spiritual and cultural beliefs, education, and life experiences. Some examples of this are: Being aware of race: Individuals may be unwilling to share information due to racially inspired mistrust. Looking at age: Younger individuals choose to engage more in shared decision-making than older adults. And education: Those with higher levels of education and literacy engage in shared decision-making more. So, the most important thing during this assessment is, do patients see themselves as sharing in this decision? Or do they want the provider just to make the decision and tell them? What we know is that when

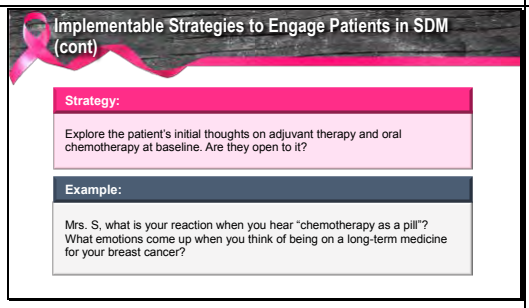
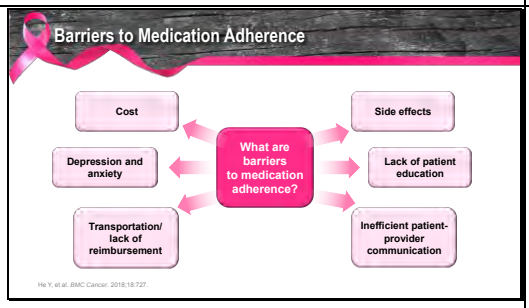
		patients feel that they can engage in the decision-making process with the provider, they have a higher likelihood of adhering to medication regimens.
12		The next aspect of this step in the process is the teaching and learning phase. This is where the nurse or the provider are able to provide the patient with all the necessary information to meaningfully participate in the decision-making process. Providers need to teach the patients this information and they need to consider the readiness of the patient, the amount and type of information that needs to be taught, and how to best teach that information to the specific patient. So this is not, "You are starting on this medication, here are 6 things you need to know about." Each individual case needs to be looked at from an individual patient perspective of, "How much do you want to learn? How best do you learn? What information do you need? And how can I best provide this to you?" So the teaching and learning phase is a very question-and-answer time with the patient that will really allow the patient to engage in the shared outcome.
13		The most important part of this process, which I alluded to, is finding balance to arrive at the shared decision between the provider and patient. We want to make sure that if there's multiple best choices for the patient, that the patient feels empowered that they have all of the information, as well as possible alternatives, risks and benefits, and all of the key components that they need to help make this shared decision. And that balance is difficult when patients don't feel

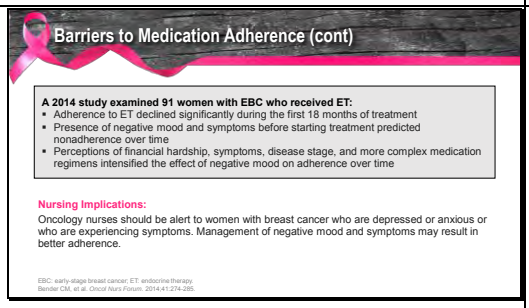
		that they are getting all the information that they need in order to make these decisions. It's a very important part of working toward the actual decision point.
14		So remember our patient, Mrs. S? She presented with a clinical T2N1a left breast invasive ductal carcinoma, hormone receptor-positive/HER2-negative. She is status post-neoadjuvant chemotherapy, total mastectomy with axillary lymph node dissection with residual disease, and now is here to discuss adjuvant therapy with antiestrogen therapy and a CDK4/6 inhibitor with Dr. X. Keeping in mind the principles of teaching and learning, what information is important for Dr. X to share with Mrs. S? a) Explanation of HR-positive/HER2-negative and pathology results from surgery and their implications on treatment selection, OS, and risk of recurrence b) Data to support the role of CDK4/6 inhibitors plus estrogen therapy in the adjuvant setting with statistics on how this impacts OS/DFS c) Implications of forgoing adjuvant treatment on prognosis d) Risks/benefits of treatment medications e) All of the above

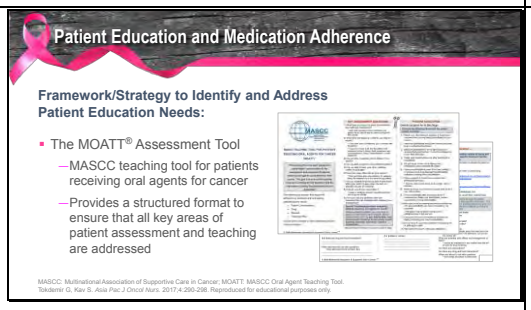
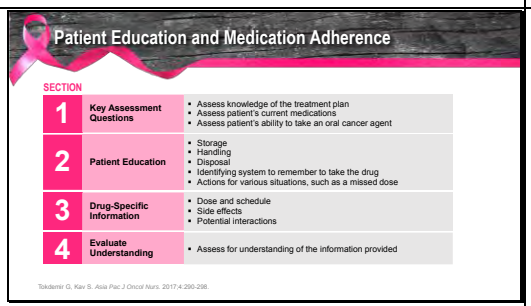
15		Ultimately, our role in shared decision-making with the patient does not end with the decision itself. The process of shared decision-making goes beyond the decision point as the patient engages in steps necessary to take action and to see these decisions through. And we can see pretty much 1 of 3 outcomes: Number 1: They say they're going to do the decision. They move through with it. That's great. They're taking the therapy. They're tolerating it well. Number 2: There may be times when patients find the action challenging or the actions required are not what they expected. In these situations, the patient may not be satisfied. They might have unresolved issues or questions, and they likely need to return to the provider to reevaluate the decision. Number 3: There also might be times where there is no action, where a patient returns to their home community and they realize that once they get home, they don't actually want to take the decision that they had agreed to take. Sometimes this happens when patients feel pressured by the provider and the power imbalance they experience when they're in the office. And so they find themselves aligning with a particular decision favored by the provider rater than going with their gut and asking questions and getting their questions answered and understanding, truly, the benefits and risks of the decision they're making. Again, this realistically is going to prompt a return to the provider to reevaluate the decision or even come in to discuss subsequent follow-up visits.

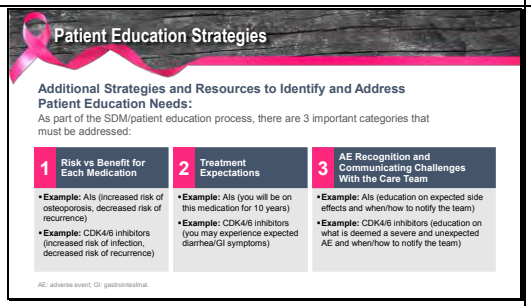
16		When we're looking at actual strategies to engage patients in shared decision-making from the nurse's perspective in these early-stage breast cancer patients, there are a lot of things that we want to make sure we take into consideration. So I'm going to talk through some strategies, and there are some examples beneath each. A first strategy goes with the assessment that we talked about. We want to make sure we're assessing the patient's understanding of the diagnosis and see where there are gaps that may exist. So one area where I like to see this in practice is, we know that when patients first have their consultation, they are told something like, "You're hormone receptor-positive," and most patients know that that means "you have to take medication after you go through chemo and surgery and all of that." But sometimes patients don't actually remember that, so it's always good to start these discussions with, "Do you recall discussing this previously? What do you recall about it?" and kind of assessing the patient's baseline knowledge.
17		A second strategy we have is we want to assess for patient characteristics and attitudes that may influence their decision to engage in shared decision-making. So one way to do this, talk with the patient and say, "We're going to talk about the next recommended steps. There is more that's recommended at this point. How are you feeling about the recommendation for further treatment?" This will give you an idea of whether or not the patients are open to having this discussion, how resistant they are at the outset, and kind of what sort of approach you need to talk

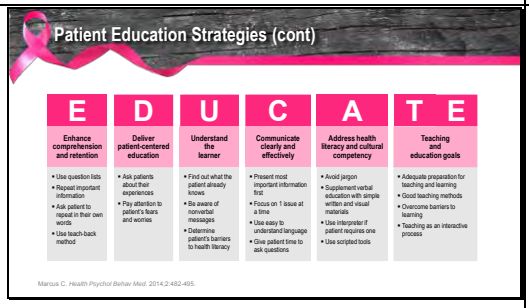
		with the patient in order to convey the education properly.
18		A third strategy is to assess barriers to treatment that may make adjuvant treatment difficult. And so, this is something that we see a lot of the time with medications for early-stage breast cancer patients, is that they have side effects that aren't going to go away after a couple of weeks. And so, we want to make sure that we're looking at the patient as a holistic being, who has a life and a job and responsibilities. And we can look at that person and their life and say, how is this medication going to specifically affect them? Do they have limitations that are going to make it difficult for them to take this medication? Do they have a very physical job where joint pain is going to be debilitating? Are they on their feet all day and don't have access to a bathroom, where something like diarrhea from a CDK4/6 inhibitor could be a real hindrance to their ability and make adherence difficult? It's really one of the most important things when we talk about these decisions with the patients, is making sure that we're not just saying, "Take this medication, it's good." It's looking at their whole life and how it's going to impact them.
19		The next strategy is when it comes to the teaching and learning phase. We want to make sure that we assess the patient in how they want to learn best and what they're comfortable hearing. Some patients say, "I don't want to know any statistics." Some say, "Read me the actual results tab of the research study you're referencing." And so it's different in these patients.

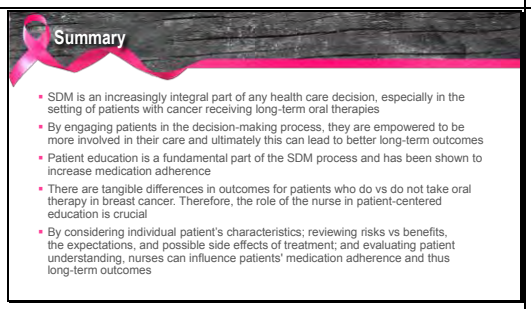
		And we want to make sure that we're assessing these patients adequately and that we are providing them the information that they want and not overproviding information to where these decisions seem untenable to them.
20		Another strategy we have is to explore their thoughts on adjuvant therapy and oral chemotherapy at baseline. We want to know, why are they open to it? And so, in this situation, a lot of patients hear the word chemotherapy and they're very triggered, especially if they've been through chemotherapy. So you want to assess how the patient responds to hearing the word chemotherapy is a pill, or, how they feel about taking a medication for a very long period of time after everything they've been through. We want to make sure that we are discussing these things up front so we can best address them and help make the patient feel that they are engaged and included in this decision and that we're not just blindly making a recommendation.
21		Overall, once the decision is made and the patient agrees to take a medication, even if they agree to start taking the medication, there are still many barriers that we experience to medication adherence. I'm going to go ahead and list a lot of the barriers that exist, and I'm going to dive into 2 a little bit more deeply. First of all, cost. We know that cost is something—medications, insurance—all that is something that can be a barrier, especially with more specialized cancer medications.

		Side effects. Again, a very common area that we know is something that can cause a patient to stop taking their medication. Depression and anxiety is something that we'll talk about a little bit further. Lack of patient education. Again, a very integral part, and there's a lot of research to support the strength of this. Transportation and lack of reimbursement when extra visits are needed and the patients aren't able to come or afford to come to the center for those. That's a big barrier to taking this particular adjuvant medication. And inefficient patient/provider communication. A lot of patients, if they feel that they are supposed to take new medication and they can't get in touch with the doctor's office if something's going wrong, that can be a big barrier for them continuing to take that medication.
22		The first subset of that we're going to discuss is depression and anxiety. A 2014 study examined 91 women with early-stage breast cancer who received endocrine therapy. Adherence to endocrine therapy declined significantly during the first 18 months of treatment. The presence of negative mood and symptoms before starting treatment predicted nonadherence over time. Perceptions of financial hardship, symptoms, disease stage, and more complex medication regimens intensified the effect of negative mood on adherence over time. The important takeaway in this for our nursing staff is that we should be very, very aware of our patients who have

		breast cancer and who have depression and anxiety and who are having these symptoms pervasive in their life when they're undergoing this new stage of adjuvant therapy. We need to make sure we're managing their negative mood and symptoms because it could lead to worse adherence. If we're addressing the cause, if we're addressing the mood by psychiatry services, medication, psychology services, that kind of support holistically, that's something the nurses are very good at acknowledging and doing; that's something that could lead to much better medication adherence over time.
23		There are a lot of tools that exist that are able to help with patient education specifically for oral chemotherapy because it's something that is very difficult for patients to understand. So I chose to highlight one of those called the MOATT assessment tool. This was put on by the Multinational Association of Supportive Care in Cancer, and basically it created a multifaceted tool that goes through multiple different sections, which we'll review, and allows for a very thorough patient education, which ultimately will influence the patient's adherence to medication.
24		The 4 categories that we have are: The key assessment questions: These assess for knowledge of the current treatment plan, the patient's current medications, and the patient's ability to take a cancer agent. Section 2 in the MOATT tool is patient education about storage, handling, and disposal of medication, as well as

		identifying a system to remember to take the drug; and actions for various situations, such as a misdoes. Section number 3 is drug-specific information—the dose and schedule, side effects, and potential interactions, be that food or other medications. And then, specifically an area for evaluating understanding and assessing understanding of the information provided above in these previous slides. There's basically an area where it's a written-down teach-back method on providing the patient with all this information where they can actually write down "this is what the medication is for, here's how I take it." Because the teach-back method is a very effective way in assessing and ensuring patients' understanding.
25		When we talk about patient education strategies, there are really 3 major things that we want to make sure we're talking about. Again, all of the education that we just provided about the drug itself, but 3 that really influence the patient's ability to continue taking the medication and to feel safe taking the medication. Number 1 is risk versus benefits. Patients want to know what the long-term effects are. So for example, with aromatase inhibitors, you want to make sure you're talking about the increased risk of osteoporosis. You want to talk about treatment expectations. That can be things like side effects or duration of treatment. With AIs, you'll be on them for anywhere between 5 to 10 years; and with CDK4/6 inhibitors, to be expecting the GI side effects that might

		come up so that patients aren't shocked when that happens. And again, if there are adverse events, we want to recognize what is happening, what is related to the medication, and how to communicate that with the care team. And so, for each of these medications, there are specific subsets of warning signs and symptoms, and those are things that we want to make sure we are communicating with patients during this education about starting a new drug so that they are very aware of how to continue.
26		Again, here's just a quick mnemonic when we talk about other ways to enhance patient education. The mnemonic is EDUCATE: E is for enhancing comprehension and retention. This is using question lists, asking the patient to repeat in their own words and using the teach-back method, as I just discussed. D is for delivering patient-centered education. Again, this goes back to shared decision-making. We want to include the patient's experiences, their fears, their worries, their anxieties, their emotions in these decisions. We want to make sure it's very patient-centered. U, understand the learner. We want to find out what they already know and determine their barriers to health literacy. Again, part of the shared decision-making model. We want to understand how they learn best. C, communicating clearly and effectively. Always want to make sure we're presenting the most important information first, focusing on 1 issue at a time, and using easy-to-understand

		language, not medical jargon, with our patients. And we want to make sure we're allowing the patient time to ask questions, again, in the teaching-and-learning phase of the shared decision-making process. This is very, very important. And it comes into play again when we're talking about patient education. A is for addressing health literacy and cultural competency. And we want to supplement verbal education with simple written and visual materials, using an interpreter if needed, and using certain scripted tools, such as that MOATT tool that we just discussed. T and E are for teaching and education goals. We want to make sure that we're using good teaching methods, overcoming barriers to learning, and using teaching as an interactive process. This all kind of comes together under 1 umbrella: improving medication adherence by making patients feel that they are communicated with while they're engaged in the decision, they're being taught in a way that they can learn, and that they're feeling very supported in these big decisions.
27		Overall, in summary, shared decision-making is an increasingly integral part of any healthcare decision, especially in the setting of patients with cancer receiving long-term oral therapies. By engaging patients in the decision-making process, they are empowered to be more involved in their care and ultimately this can lead to better long-term outcomes.

		Patient education is a fundamental part of the SDM process and has been shown to increase medication adherence. There are tangible differences in outcomes for patients who do versus do not take oral therapy in breast cancer. Therefore, the rule of the nurse in patient-centered education is absolutely crucial. By considering an individual's patient characteristics; reviewing the risks versus benefits, the expectations and possible side effects of treatments; and evaluating patient understanding, nurses can influence patients' medication adherence and thus their long-term outcomes.
28		Thank you so much for listening to this activity.