

# Listen Up!

## Examining Communication and Optimizing Extended Adjuvant Breast Cancer Care

### Educational Objectives

After completing this independent study, the participant will be able to:

- Summarize current adjuvant hormonal agents and the research that is influencing treatment options.
- Identify common educational needs related to breast cancer care and nursing actions that can optimize patient teaching.
- List two factors that influence patient satisfaction with communication and teaching.

### Continuing Education Information

ONS's Approver Unit has approved this independent study for 1.6 contact hours through August 1, 2007. The American Nurses Credentialing Center's Commission on Accreditation accredits ONS as an approver of continuing education in nursing.

ONS's approval of CE credit for this monograph does not imply endorsement of Novartis Oncology, nor does ONS assume responsibility for the educational content of this monograph.

### About This Monograph

This monograph is an independent study for oncology nurses interested in examining communication as a key to optimal care for women with breast cancer. The study reviews early breast cancer, hormonal treatment, extended adjuvant hormonal therapy, and the importance of communication to optimize care. The text begins with information and data regarding adjuvant treatment of breast cancer. A narrative of a dramatic monologue presentation from the 30th Annual ONS Congress follows that examines the doctor-patient relationship and the critical role of the oncology nurse. A discussion of meeting patient educational need, achieving patient satisfaction

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and making treatment decisions in the adjuvant setting is presented. The piece concludes by capturing a clinical discussion of specific questions and answers relevant to optimizing breast cancer care.

This independent study is also available on the Internet at [www.oesweb.com](http://www.oesweb.com). If you complete the online post-test for CE credit, you cannot submit a mail or fax post-test for CE credit, and vice-versa.

# Listen Up! Examining Communication and Optimizing Extended Adjuvant Breast Cancer Care

## Introduction

This monograph is an independent study for oncology nurses interested in a basic review of adjuvant aromatase inhibitors and extended therapy for treatment in estrogen- and progesterone- positive breast cancer patients. Communication as a key factor in patient education, treatment decisions, and patient satisfaction will be emphasized. A humorous review from the patient's perspective will be used to describe a personal side of communicating with the physician. Nurses will be able to apply these communication concepts directly to the care they provide.

In 2005, an expected 211,240 new cases of breast cancer will be diagnosed, and 40,410 women will die from the disease. This represents a lifetime risk of one in seven (American Cancer Society [ACS], 2005). The risk factors that contribute to the development of breast cancer include increasing age, a personal or family history of breast cancer, a personal history of benign breast disease, early menarche or late menopause, nulliparity, obesity, and alcohol consumption (ACS, 2005).

While treatment options for breast cancer include every known modality of therapy, each individual patient may face a multitude of decisions and treatment options. Treatment decisions are individualized based on disease pathology, tumor size and location, the presence of metastatic disease, available clinical trials, and patient preferences. For the purpose of this discussion, only the roles of **adjuvant hormonal therapy** and **extended adjuvant hormonal therapy** will be explored.

### Enhanced Learning & Guide for Facilitators

OES believes in continuing nursing education and strives to provide a variety of high-quality educational programs and opportunities that appeal to a variety of learners. Whether you prefer live events, monographs, teleconferences, or web-based programs, OES wants to meet your educational needs.

To assist nurses in their independent learning and to promote application to clinical practice, OES has developed a unique layout for this monograph. Nursing implications have been summarized and highlighted throughout the text, allowing quick reference and direct application. A glossary of unfamiliar terms has been included in the back, and glossary terms are identified with **bold underlined** type throughout the text. A list of the medications mentioned has also been compiled and will serve as an additional reference tool.

OES consistently receives feedback on the value of continued learning through peer participation in journal club discussions. To assist group discussions, OES offers a new model for monograph learning modules. Once individuals have completed their continuing education activity, independent of group discussion, OES encourages group facilitators to use a number of call-out boxes with specific **Points for Group Discussion**. These talking points can be used to stimulate conversation, analysis, group discussion, or further investigation.

# Breast Cancer in the Adjuvant Setting

**E**arly breast cancer is defined as stage I or II disease. In stage I breast cancer, all detectable cancer is, by definition, restricted to the breast. For women with stage II disease, local lymph node involvement may be present and may be removed surgically. Nevertheless, any woman with early breast cancer may have undetected **micro-metastatic** deposits of the disease. This micro-metastatic disease may take several years to develop into clinically detected recurrence. In fact, recurrence of breast cancer peaks during the first five years after surgery and then declines slowly over the following four decades (Simpson, Curran & Perry, 2004). **Adjuvant** therapy refers to treatment offered to women with early-stage breast cancer after primary/curative therapy, usually involving surgery, in an attempt to reduce recurrence rates.

Since the growth of at least half of all breast cancers depends on the action of estrogen, systemic adjuvant hormonal therapies have become a mainstay for the treatment of **hormone-receptor-positive** (HR+) breast cancer. Hormonal therapy is used to prevent estrogen stimulation of breast cancer cells by blocking the **estrogen receptor** (ER) or by suppressing **estrogen synthesis** (Grana, 2003). The effectiveness of adjunct hormonal therapy is acknowledged by the National Institutes of Health, which recommends its use in women with hormone-receptor-positive breast tumors regardless of their age, menopausal status, axillary node involvement, or tumor size. (Grana, 2003) Hormonal therapy is not indicated for women with **hormone-receptor-negative** (HR-) tumors (Winer et al, 2005).

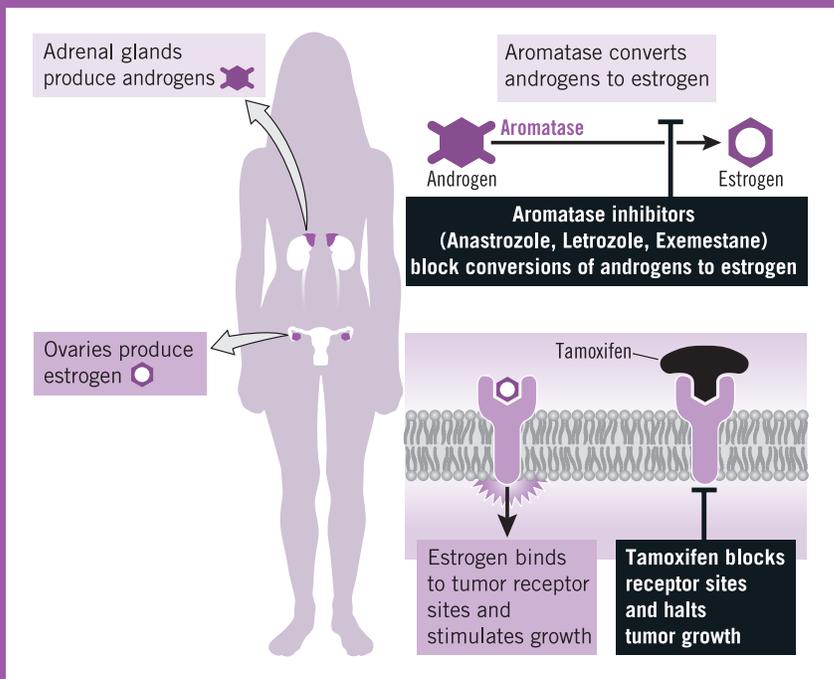
One of the first agents used for hormonal therapy was **tamoxifen**. This agent inhibits estrogen from binding to the estrogen receptor and is known as a **selective estrogen receptor modulator** (SERM). Postoperatively, patients who have taken tamoxifen had reductions in their risk of recurrence of 47%, their risk of death of 26%, and their risk of contralateral breast cancer of 47% (Grana, 2003). The use of adjuvant tamoxifen significantly

improves the ten-year survival for these women. Because of its efficacy, adjuvant tamoxifen for five years is the current standard of care for women with early-stage ER-positive breast cancer (Smith, 2004).

Tamoxifen has been in use over twenty years and has offered significant benefit to hundreds of thousands of women. Unfortunately, however, 50% of all breast cancer recurrences occur after patients have completed five years of adjuvant therapy with tamoxifen (Smith, 2004). Evidence does not support extending treatment with tamoxifen beyond five years, as demonstrated in the NSABP (National Surgical Adjuvant Breast Project) B-14 trial (Fisher, Dignam, Bryant, & Wolmark, 2001). Documented side effects of tamoxifen include an increased risk for endometrial cancer and thromboembolism. Some of these adverse events are thought to result from the partial agonist activity of tamoxifen at estrogen receptors located in non-breast tissue such as the bone, liver, and endometrium. Other side effects of tamoxifen include mild nausea, hot flashes, and tumor flare that usually occurs during the first month of therapy, causing discomfort or erythema at metastatic sites (Grana, 2003; Smith, 2004).

## Aromatase Inhibitors

Aromatase inhibitors are another class of hormonal agents that suppress estrogen synthesis. Recently, third-generation **aromatase inhibitors**, including letrozole, anastrozole, and exemestane, have demonstrated clinical benefits compared with tamoxifen for the hormonal treatment of primary and advanced breast cancer. Additionally, this class of drugs has shown an increase in efficacy and an improved safety profile over tamoxifen in postmenopausal women with ER-positive disease. Given their efficacy in advanced breast cancer, it was thought these agents could be effective for early breast cancer or as extended therapy after tamoxifen use, and clinical trials are investigating that question.



**FIGURE 1**  
**Hormonal Therapies -**  
**Mechanisms of Action**

treatment for postmenopausal women with ER-positive breast cancer include an aromatase inhibitor as initial therapy or after treatment with tamoxifen (Winer et al., 2005). Optimal duration of aromatase inhibitor therapy remains unknown, and no data exists to support initiation of tamoxifen after a course of aromatase inhibitor treatment (Winer et al., 2005).

Aromatase inhibitors block the effects of estrogen on breast tumor cells through a different mechanism of action than tamoxifen, as shown in Figure 1. **Aromatase** is an enzyme complex that is necessary for estrogen synthesis and acts by converting androgens to estrogens such as estrone and estradiol (Grana, 2003). This conversion accounts for a relatively low but stable level of circulating estrogens in post-menopausal women. Because aromatase inhibitors block this conversion, levels of circulating estrogen are greatly reduced. Therefore, aromatase inhibitors lack the agonist effects on the endometrium and also have a significantly decreased risk of thromboembolism compared to tamoxifen. At this time, three oral aromatase inhibitors are available for clinical use: letrozole, anastrozole, and exemestane. These agents are more highly selective for the aromatase enzyme than the first and second generation of agents (Buzdar, 2004).

Clinical trials with aromatase inhibitors for extended therapy have been conducted or are ongoing, with various goals and designs. Trial strategies include: a) using aromatase inhibitors after the patient has taken five years of tamoxifen; b) using aromatase inhibitors the first five years after surgery; or c) starting with two and one-half years of tamoxifen and then switching over to an aromatase inhibitor for another two and one-half years. Four phase III randomized adjuvant trials have evaluated various third-generation aromatase inhibitors compared to tamoxifen or to placebo after two to five years of tamoxifen therapy and will be reviewed briefly here (see Table 1). Based on this data, the American Society of Clinical Oncology (ASCO) recommends that optimal adjuvant hormonal

The pivotal trial showing efficacy of extended adjuvant therapy, the use of an aromatase inhibitor after five years of tamoxifen, was the MA-17 trial (Goss et al., 2003; Smith, 2004; Gross, Ott, Lindsey, Twiss, & Waltman, 2002). Over 5,000 patients were enrolled in this trial and were disease free after 4.5-6 years of tamoxifen therapy. These post-menopausal patients were randomized to letrozole or placebo for five additional years after tamoxifen. The primary end point was disease-free survival. Treatment groups were well balanced. Ninety-eight percent were ER/PR-positive, 50% were node-negative (and 50% node-positive), and 46% had chemotherapy before tamoxifen therapy. This trial met the primary endpoint at the first term of analysis, leading to an early unblinding of the trial. At 2.4 years, letrozole showed a 43% reduction in risk of recurrence and a 39% decrease in distant recurrence compared with placebo (Goss et al., 2003; Winer et al., 2005).

An extension phase has been planned for the MA-17 study. Beginning May 2004, women who participated in the letrozole arm of the original trial, and who remained cancer-free after five years, have the opportunity to enroll in the extension phase. These women will be re-randomized to receive either letrozole for an additional five years or placebo (Goss, Ingle, & Pater, 2004).

The International Exemestane Study (IES) was a double-blind study of over 4,700 women who had received two to three years of tamoxifen. The women were randomized to continue tamoxifen or to receive exemestane to complete a five-year course of adjuvant hormonal therapy. The trial revealed a significant reduction in recurrence, occurrence

**Table 1. Clinical Trials: Aromatase Inhibitors**

	MA-17	IES	ATAC	ITA
Design	Double-blind randomization to receive placebo or letrozole for 5 years after completion of 5 years tamoxifen therapy	Double-blind randomization to continue tamoxifen or switch to exemestane to complete a full 5-year course of therapy	Double-blind randomization to anastrozole, tamoxifen, or a combination of the two agents	Open label randomization to receive tamoxifen or anastrozole to complete a full 5-year course of therapy
Participants	*Over 5000 women who had completed 4.5-6 years of tamoxifen	*Over 4700 women who had completed 2-3 years of tamoxifen	*Over 9000 women	*Over 448 women who had completed 2-3 years of tamoxifen
Results	Disease free survival benefit revealed for the letrozole arm within 2.4 years; trial un-blinded and follow up continues	Significant reduction in recurrence, contralateral breast cancer and death after an average 30.6 months of follow-up	Improved safety profile for anastrozole compared to tamoxifen with fewer contralateral breast cancers noted; no advantage with combination therapy noted	Safety and clinical benefit of switching to anastrozole demonstrated; statistically significant improvement in disease-free survival for women on anastrozole after 52-month follow up

\*All women were post-menopausal, disease-free with hormone-sensitive tumors  
*Note:* Adapted from Winer et al., 2005; Boccardo et al., 2005.

of contralateral breast cancer, or death in favor of the exemestane arm after an average of 30.6 months follow up (Coombes et al., 2004; Winer et al., 2005).

The ATAC Trial (Arimidex, Tamoxifen, Alone or in Combination) was a double-blind study that enrolled over 9,000 patients. Patients were randomized to receive tamoxifen alone or anastrozole alone, or tamoxifen in combination with anastrozole. This is the only trial to date to assess combination hormonal therapy – which showed no advantage over anastrozole alone. A better safety profile was found with anastrozole compared to tamoxifen. Overall, fewer invasive contralateral breast cancers occurred with anastrozole compared with tamoxifen alone or in combination (Baum et al., 2002; Buzdar, 2004).

The ITA (Italian Trial Anastrozole) was a much smaller, open-label study with patients who had received two to three years of tamoxifen and were randomly assigned to either continue treatment with tamoxifen for a full five years or to receive anastrozole. Accrual of 448 women was obtained. After 52 months of follow up, the trial demonstrated significantly improved progression-free survival and event-free survival (P=0.001 and P=0.0001, respectively). Safety (adverse events) was comparable in the two arms, but six women developed endometrial cancers in the tamoxifen group, while only one case was reported in the anastrozole group (Boccardo et al., 2005). It is not known if aromatase inhibitors are interchangeable in clinical practice and if current clinical trial data with aromatase inhibitors can be extrapolated to each

agent. Anastrozole and letrozole have similar chemical structures and are referred to as non-steroidal agents with partial estrogenic activity. Exemestane is a steroidal agent that binds irreversibly to the aromatase enzyme with no estrogenic activity.

### Points for Group Discussion:

- Why is research continuing in the adjuvant breast cancer population? (50% of breast cancer recurrence occurs after five years of tamoxifen therapy, high risk side effect profile for tamoxifen, apparent drug resistance with tamoxifen beyond five years of therapy)
- Discuss the action of tamoxifen as compared to aromatase inhibitors and use Figure 1 to help clarify why aromatase inhibitors are not used in the premenopausal population.
- Summarize the four clinical trials listed in Table 1 to identify key conclusions drawn from each. Discuss how the trials' designs help answer specific research questions regarding the use of aromatase inhibitors (AIs). What questions can you identify that remain? (Can AIs be interchanged? What is the optimal length of therapy? Should AIs be used as initial therapy? Why or why not? See Winer et al. [2005] for a more thorough discussion.)

### Side Effects and Management for Aromatase Inhibitors

It is known that aromatase inhibitors reduce bone density and may cause hypercholesterolemia due to the decrease in circulating estrogen levels. Studies have been conflicting, and further monitoring is needed (Winer et al., 2005). Aromatase inhibitors' effect on lipid profiles and cardiac clinical outcomes as compared to tamoxifen will also require more monitoring. It is known that tamoxifen decreases cholesterol levels; however, its influence on cardiac events is not established (AstraZeneca, 2005).

Letrozole is metabolized by the liver, and dosages should be reduced by 50% for patients with severe hepatic impairment (Novartis, 2003; Harwood, 2004). Although anastrozole hepatic metabolism is 85%, no dose change is recommended for mild-to-moderate hepatic impairment (AstraZeneca, 2002). Exemestane is metabolized by the liver cytochrome P-450 3A4 pathway, and the safety of chronic exemestane dosing in patients with moderate to severe hepatic impairment has not been studied (Pharmacia and Upjohn/Pfizer, 2004).

All three third-generation aromatase inhibitors have been well tolerated, with a small number of women discontinuing treatment because of side effects compared to women on placebo or tamoxifen. Side effects related to aromatase inhibitors include hot flashes, night sweats, bone loss, mild nausea, body aches, and vaginal dryness or other effects on sexual function (Viale, 2005). Education plays an important role in helping women manage these side effects and includes helping women explore various interventions. Continual assessment regarding a woman's side effects and their management is essential.

While there is a great deal of research and anecdotal information regarding the management of menopausal symptoms such as hot flashes, night sweats, vaginal dryness and sexual dysfunction, it is unclear how well this

information can be extrapolated to the breast cancer population. For example, many of the hormonal supplements that may be offered for vaginal dryness may be contraindicated for women who have had breast cancer. Vaginal lubricating agents are still appropriate, and some practitioners may offer topical estrogen preparations. However, patients are encouraged to discuss any interventions with their healthcare providers. Other non-pharmacological interventions such as exercise, warm baths, local application of ice or heat, frequent rest periods, relaxation techniques, or massage may also be helpful in managing body or muscle aches related to menopause.

While the occurrence of hot flashes from aromatase inhibitors seems to be less than that reported with tamoxifen, there is still an increased report compared to placebo (Harwood, 2004). Interventions used in the management of hot flashes may include behavioral strategies such as relaxation training, the use of aromatherapy, cooling sprays that contain essential oils, dressing in layers, or exercise. Certain dietary changes, including the avoidance of caffeine or alcohol, have also shown some benefit in the management of hot flashes in the general population. Increased soy consumption remains controversial. Increasing vitamin E intake to 800 to 1200 IU per day may also help to decrease hot flashes. Prescription medication with non-hormonal agents such as clonidine or antidepressants may help decrease hot flashes, but hormonal agents are contraindicated ([www.healthy-diets.us](http://www.healthy-diets.us); [www.my.webmd.com](http://www.my.webmd.com)). Research is still needed to evaluate the effectiveness of these interventions and others because there is no definitive conclusion regarding how effectively they decrease the occurrence of hot flashes for women taking aromatase inhibitors.

Aromatase inhibitors cause an altered hormonal environment that results in increased bone loss. **Osteopenia** or **osteoporosis** assessment must be discussed with patients. A baseline bone density test should be performed

with periodic rechecks. Weight-bearing exercises should be performed at least 20 to 30 minutes, three to five times a week, to help maintain skeletal health (Gross, Ott, Lindsey, Twiss & Waltman, 2002). Calcium supplements of 1500 mg/day (in divided doses: 500 mg x 3) with vitamin D 400 IU are suggested for women at increased risk for bone loss, smoking cessation is strongly encouraged, and oral or IV bisphosphonates may be added (Swenson, Henly, Shapiro & Schroeder, 2005; [www.my.webmd.com](http://www.my.webmd.com); Smith, 2004). Clinical trials are currently underway to evaluate the effectiveness of concomitant IV bisphosphonate and aromatase inhibitor therapy to minimize osteopenia occurrence (Smith, 2004).

## Nursing Implications for aromatase inhibitor therapy:

- Nurses should be familiar with the various agents available for hormonal therapy and the continued risk for breast cancer recurrence after curative treatment.
- Patient education should include side-effect management.
- Exercise is an important component of managing multiple side effects including hot flashes and bone loss
- Letrozole dosage should be decreased for patients with severe hepatic impairment.

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FL, April 30, 2005: "Listen Up: Examining  
Communication and Optimizing Extended  
Adjuvant Breast Cancer Care."

# Doctor, Doctor, lend me your ear.

**An examination of the doctor-patient relationship.**

A DRAMA BY DR. MARISA WEISS.

Now you asked me today to speak to all of you amazing nurses about the doctor/patient relationship from the perspective of the doctor. Of course, I could do that. But would it be okay with you if I could do this from the perspective of the patient, because you and I, we've all been patients too. Is that okay? All right, this will take a minute (removes her lab coat and clothes revealing just a patient gown underneath).

When would you ever choose to wear something like this to an important meeting about your future? I mean, am I the only one? You have all been there too – and you're all here today. You're amazing oncology nurses; so dedicated. How many of you have been patients in the last month, two months, six months or a year, raise your hand? Seen a doctor? See, wow!

All of you were patients. I'd like to ask you to put the oncology-nursing piece aside for a second. Let's put ourselves in the shoes of the patients. Let's try to get a better sense of what they're thinking, what they're feeling, so we can work together to try to give them the best relationship with their doctor. I'm here to talk about the doctor/patient relationship, because I'm a physician, and I've also been in the role of a patient. I haven't had the privilege of being a nurse, although I have a few colleagues who have both degrees. Now it's only through working together, nurses and doctors working with patients together, that we can accomplish what we need to, which is to bring back the sacredness to the relationship between women and their doctors. Of course, the doctors' don't work alone. They work with a team, and you're so absolutely central to that team.

I'm really thrilled to be here today to talk about the doctor/patient relationship and why it's so important. But, why it's so complicated, intimidating and so hard to negotiate from the patient's point of view. I work through [breastcancer.org](http://breastcancer.org) and try to bring the best medical information to women worldwide. Of course, that medical information is only valuable if the patient brings it to her doctor and/or a nurse. You as nurses, we as doctors, can put that information into the right context; know if that information applies to our patients; help the patients implement that information; and over time, reinforce it all.

There's only one of you. When you're a patient, or when we take care of the patients, there's only one of each patient that come to us. The patients bring us on their team to protect and cherish their lives. When I'm in the role of a patient, I'm mostly thinking about my children's lives, as the mother of three small kids, because, if something happens to me, I worry what's going to happen to my children.

For a woman who has breast cancer, there are so many new treatment options, so many new opportunities for surgery, radiation, chemotherapy, immunotherapy, hormonal therapy, physical rehabilitation. That means there are many different experts on the team. For a lot of the people, that can feel very fragmented, and the woman might feel like she is the quarterback for her own care. This is very overwhelming and confusing – particularly when you're feeling inadequate and anxious. The fact is that the care is still delivered within the context of a relationship.

Every relationship is a lot of work. You all have many different relationships in your lives. The relationship that you have with your doctor is a really complicated one. When you think about it, it is so important and sacred. You meet this person, this stranger, and you put your life in their hands. It's the doctors' terminology — their mumbo-jumbo. The doctor is usually dressed, and you're wearing one of these (pointing to the patient gown). The patient is the one with the healthcare concern; the doctor is presumably well. Then, just think about all the things you have to do as a patient just to go to the doctor, and make it all happen. How about if I take you with me when I go to see my doctor?

For me, it always starts with a sleepless night, because I worry. With lights off and no distractions, my ceiling becomes like a big screen for this horror movie that I'm imagining is going to happen the next day. That is always when I see my husband the most: sleeping. Then there's that next morning when you wake up, and you have to get ready; you start shaving those legs. Swear to God, two years ago, I went to the gynecologist; I took off my clothes and I looked down. I had forgotten to shave my right leg. There I was: half man, half woman.

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Then what if you have your period, do you still go? A lot of women miss that appointment because they're embarrassed and they believe they can't be examined when they have their period.

What do you wear? Is it time for leopard? Is it time for a suit? Does it even matter? Because when you're seen, this is what you're wearing (patient gown). How many of you have to get your kids up, out of bed, fed, keep them from killing each other, on the bus, out the door; and then you have to fight traffic just to get to that doctor's office on time. Then you go to the front office, and you have to get the receptionists' attention: "Over here! Over here!"

You're finally signed in; everything is moving along okay; here we go. And, then you wait...and you wait some more. You know as nurses that your life at the hospital is a very busy place, and things usually don't go on schedule. So, you wait; that's fine. But after a certain point, sometimes you wonder, what are they doing? Are they playing poker or something?

You guys (nurses) are the eyes, the ears, the talent, the energy, the everything, and this is the first contact a patient has with a team member who is really there to take care of her.

Then you wait some more. All of a sudden, the secretary comes out and blasts your name. "Is there a Marisa Weiss here? A Marisa Weiss somewhere over there?" Say goodbye to privacy! Those HIPPA Laws help in many ways, but this is one place where we haven't figured out how to preserve a patient's privacy. Now, my family — as it turns out — has the breast cancer gene (which I found out years after I became a breast cancer doctor). Anyhow, when my family went to get our results at the Fox Chase Cancer Center, I walked in the side door hid-

ing behind a newspaper to protect my privacy from a lot of people I knew in that waiting room. We scurried into the corner of the waiting room; we thought we were doing such a good job of hiding. Then our name was called out, blasted over the loudspeaker three times. I wish that together we could come up with a solution for that.

So after your name is called, you get to meet the nurse, this wonderful person. Please, why don't you pat each other on the back? I say thank you to you. You take such phenomenal care of the women out there who have breast cancer. Thank you so much — really. You guys are the eyes, the ears, the talent, the energy, the everything, and this is the first contact a patient has with a team member who is really there to take care of her. This is really the time for patients to tell you what's on their mind.

I remember one time I was taking care of a woman I had taken care of for about 10 years. When I asked, "Mary, how are you? What's going on with your family?" Mary was really distant. I really didn't know what was going on. Finally, 10 minutes into meeting with her, I said, "Mary, what's on your mind? You seem so preoccupied." She said, "What about that bone scan?" "Bone scan? What bone scan?" "I saw Dr. Cohen last week; he got a bone scan." "What does the bone scan show?" I said, "Oh, Mary, I wish you had told me that was on your mind, because if we had known that up front - my nurse and I, we would have addressed it right away to discuss your concern and move on to other things."

Now as a patient, as soon as the nurse leaves the room, I'm at the paper towel rack – blotting my armpits — getting rid of any sweat that might possibly have built up from all that rushing around. Got to get ready; got to get ready. And then you wait. You know there's that chart sitting there, and it might actually have the information you're looking for. You're allowed to read it. It's just that when that doctor walks in and catches you — all of a sudden you feel like a criminal, when it's your chart. You do have the right to read your own records. So that's another funny thing with the patients; how can you give them access to their information when they need it?

Now, sometimes when the doctor walks in, he or she looks like one of your own kids. How are you supposed to feel confident when the doctor looks 10 years old? If you're the nurse working with that doctor, guess what's going to happen? The patient is going to be looking right to you. Sometimes when that door opens, a whole team of people comes in, this huge ratio between this little patient and this whole team of people. I think it's okay for the patient to say, "You know what, it's been a really hard day for me. I'd really appreciate just having you, the doctor, and you, the nurse, come in and be here with me. I just can't handle the whole audience." If you do let these people come in, then you should know who they are. They should be introduced.

One solution is for the patient to bring her own team; build her own ratio. There's a problem here though, and that is a patient might be bringing a lot of people with them, and the doctor or nurse, they don't know what's okay to reveal in front of these people. All the HIPPA laws, right? So that might actually inhibit the conversation. Another thing that happens is that many of those people have been given job descriptions. Jim's going to ask about this question. Sue's going to say this; Aunt Martha is going to say that. How many times do they actually follow the job description? Never. Someone is asking, "Doctor, can you look at the mole on my neck." They're all asking all kinds of questions. It just doesn't always work. Sometimes it can be a circus. So a patient needs to really think carefully who to bring with her. It's her team.

I think that any important meeting should start when two people greet each other. I remember bringing my sick kid to the pediatrician for an unscheduled visit. I was so happy to be put into the schedule. We're waiting and waiting and waiting. We go into the patient examination room. The door opens. This guy walks in reading the chart, like this. Someone I've never met before. He starts talking like this from the chart to my kid. We both expected the regular doctor. So I just

felt this anger rise inside me, and I was really upset. The guy didn't even introduce himself. So I didn't know what to do. I just stopped the conversation. I said, "Excuse me, I don't know who you are. I'm Marisa; this is my kid, Elias. What's your name?" He stopped, and he gave me his name. It turned out to be a really good thing to do because it got rid of my anger right up front. If I had stayed angry, I wouldn't have been able to hear what he had to say. Also, my kid was really worried, and he would have been upset. It would have been a much harder exam. I could also teach my kid that you can speak up. So that ended up being a good experience, but sometimes you have to live through these things to get there.

Patients have to really prepare themselves before they go to the doctor appointment. As a patient, you need to let your doctor know how he or she can be most helpful to you. Prepare your questions and write down symptoms, on one piece of paper, not on the back of a hand or on some little piece of paper you're so sure is in the bottom of your pocketbook. What will happen? You'll never find it, and you'll never get your questions answered. That defeats the whole reason why you're there. You've got such a short time to get these questions addressed.

Now, I think what's really key, and I know you know this from a patient point of view and a nursing point of view, is that after you ask a question, you have to stop and listen to the answer. This is a relationship between two people. You know how nervous everyone gets. Sometimes they concentrate so much on how to ask the question; they're so relieved after they ask the questions that they tune out your answer. They're thinking about how to ask the next question, and they're not really listening to your answer. Or they're so nervous they keep talking after they ask the question, and they keep talking. They don't even hear what you're saying. There's no way to get in to answer their question. There's no airtime to say, "Well, let me answer your question

One solution is for the patient to bring her own team; build her own ratio.

for you.” When we’re talking to a doctor, it’s really important to do that, just as it is when a patient talks to a nurse.

I think that after you get an answer to your question, it’s important to say, “Thank you. Thank you. That meant a lot to me. That really helps me better understand what I’m dealing with.” If you flatter a doctor - I don’t know if you guys know, doctors have really big egos. Do you know that? It’s one of the secrets that I want to share with you today. If you thank a doctor after a question is answered, you’ll get to more answers on your list.

Patients do need to know that they have to put the most important questions at the top. It’s also okay for the doctor or the nurse to say, “You know what, you have a lot of questions today; and I’m sorry I don’t have enough time to get to all of them today.” Or the patient to say, “I probably have too many questions today. Is there another place I can get them answered, other physicians, other

have that person take notes. In that case, make sure you introduce this person and let the doctor know what kind of information he can reveal to you in front of the visitor.

I think how far away you sit from a doctor has an impact on what you’re willing to talk about. There are some issues that are very sensitive. Let’s just say you’ve had breast cancer; you’ve gained weight; you’ve lost your hair; you’re in discomfort; you’ve got no energy; your sex life stopped upon finding out you have a diagnosis; you want to know how to rekindle that part of your life. You’ve gone to great lengths; you tried to figure it out on your own, and you thought, maybe, just maybe that doctor might know something that you really could benefit from.

So, you could move your chair a little closer. How close would you want to sit? What is your comfort zone? Is across the room good? Or you want him on your lap? You have to decide. Sometimes when you’re talking to

## You know how hard it is to listen, understand and remember when you are feeling so anxious and worried about your future?

nurses on the team, physical therapists on the team, other people I can direct my questions to? Shall I make another appointment with you? Can I call you on the phone? Do you take email? Shall I fax you something?” Try to have some sort of action plan at the end to deal with the unanswered questions.

You know how hard it is to listen, understand and remember when you are feeling so anxious and worried about your future? You can take notes, but then you lose the eye contact, the body language. You can bring a tape recorder - you know how much doctors love that. But if you flatter a doctor and you say, “Wow, what you have to say is so great, and when I go home, I want to remember all of it. Can I record your voice so that later on I can play it for my husband, my daughter; then they, too, can hear what you have to say?” In response, the doctor or nurse will usually say, “Okay, thank you. Sure, right, yeah, of course.” You can bring someone with you and

your doctor, you can just feel yourself shrinking and that you’re losing your power. You feel so inadequate and helpless, like you’re a kid again. Sometimes, as a patient, you just see your life racing away, and you’re growing older by the second; before you know it, you feel like you’re as old as your own mother.

What about the time that you can’t get your doctor’s attention? They’re not listening. They’re on the phone while they’re talking to you. What do you do in a situation like this? Well, you can say, “I’ll wait for you to be off the phone. Thank you so much, I need your full attention. I’ll wait for you to be off the phone.” Then you just stop talking. Or it might be, as you know, that this doctor might be talking to your other doctor. This might be a phone call about you, and they’re clarifying, is that margin positive or negative? What did that PET scan show? What were the hormone receptors? Well, that’s a great welcome phone call in that situation.

Now, there is something we never talk about, something very taboo, and that is when we're worried, and we're anxious, and our mind can't stay in there for every little second, it will wander. I can tell you, it only takes a millisecond. But while you were totally distracted, you may have missed everything the doctor just said. So it's okay; you can say, "Can you repeat that last sentence. It's so important to me. Could you repeat that last thought so I that I get it completely," and just go on.

We've had a chance to talk. Now it's time for the physical exam. I always like to see my doctor wash his or her hands before he touches me. My house is a messy place. I've got these three kids; I've got two dogs; I'm from a big family that's in and out. I don't really care. I can't care about everything, but that hospital has to be clean. It's part of taking care of somebody - not just the doctor, but everybody else who works for the doctor, the clean uniforms, the signs and the symbols and the expression of professionalism. I like that when I'm there for a serious problem.

I get invited to speak a lot of places, but I don't for a lot of reasons and one reason is because I'm afraid of flying. I remember one time I was taking this flight somewhere, and I was looking for those professional uniforms that gave me the confidence I needed to get on that plane. I'm looking for the blue uniforms, the little gold pins. What did I see? Khakis, sneakers, polo shirts. The flight attendants were all casual. That didn't work for me. I like to see serious professionalism when it comes to something that I get worried about.

Back to the physical exam, I don't know if you guys know - for example, the gynecologic exam, very embarrassing. That embarrassment is a big reason why a lot of women don't go to their doctor. I thought of a little trick I'd share with you that helps me get over that. What I do is I just imagine the doctor in stirrups instead of me.

OK, we've had a chance to talk, have been through that physical exam, now it's time to bring it all together. I look up and, ooh, now that's a serious face on my doctor! Something terrible is going to happen here. I see that serious face and I think, "That's it, I'm dead. I'm buried. There's my husband with another woman; and there's that witch reading my kids a bedtime story." I got the whole picture down. Now she's cleaning out my closets. Okay.

You look up and you see that serious face, and you know what, you missed everything he just said. So when you do start listening to what he's saying, you think, "Wow, this guy really cares about me. He's listening to me. He's responding to me. He's telling me he's going to be there.

His staff is there. They work as a team. I can call; they'll be accessible. They'll give me my results. Wow, this is starting to feel good. Good! Good! Good! I'm feeling taken care of. I feel like they're responding to me. Wow!" And I begin to feel the beauty and the special quality of the doctor/patient relationship when it's working the best. I think you can agree that excellent care does require this excellent communication.

I think you can agree that excellent care does require this excellent communication.

You can't get everything in a doctor, but you've got to be able to relate. It's not just between you and your doctor, it's between you, your doctor, and the other doctors, the nurses, and other members of his staff. You want to know that everyone is on the same page. It's reassuring to know that the doctor is going to pick up the phone and make those phone calls. If a test is requested, that the other doctor's names are written on the prescription sheet so that they get copies of the reports, so no one is jumping around scrambling trying to get the results.

It's also after you leave the doctor's office getting your questions answered, or getting refills brought in, so you call up and you speak to the secretary. It's so important, this person on the team, the secretary, to give her the information you're seeking; if it's a test, what test? Where

was it done? When can they call you back? What numbers? What time can they call? Can they leave a message on your answering machine?

If it's about a prescription, what medication? Do you have allergies? Where is your pharmacy? What's the phone number? Are you calling the doctor who's been prescribing it over time, or is that doctor on vacation; you're trying to jump to another doctor? It's, of course, always best to go back to the doctor and the nurse who are prescribing it over time for continuity of care.

Here is an example of a dictation that failed because of the words that were used. "Dear Mrs. Smith, I tried calling you at home and at work and was unable to reach you. I want to advise you that your CT scan, it showed no evidence of cancer, just aseptic necrosis." This patient of mine got this on a Friday night and was so worried she was going to die by Monday morning, she called me up, and she asked, "What does this mean?"

It was one of those moments that I realized that we need to do a better job to give women a common language with their doctors and their nurses. That's when breastcancer.org designed the Celebrity Talking Dictionary. We got over 60 celebrities around the world to share their voices to say over 1,000 breast cancer terms so women can better hear what you, the nurse, and the doctor just said, know what the word means, and be able to pronounce the word properly when asking a question. It's been an amazing resource, and I'd really advise you to send your patients there. Before we can have good communication, we need to have a common language.

Second opinions. A second opinion is the opportunity to get more information from another source so you can make the best decision possible and also feel most comfortable with the decision you've made. When patients seek different opinions, sometimes you come up with all

these different answers; they may be conflicting; you don't know how to sort them out; and you have to work with your team to come to a point where you feel resolved about a decision you're making.

Sometimes going through that second opinion is a chance to shop for a new doctor – maybe because you feel your current doctor is arrogant, doesn't listen, is inaccessible, you can't trust him, you don't like him, or something he said or she said really annoyed you so you're looking for somebody else. I'll tell you what's really interesting

is that switching doctors is a hard thing to do, even if you don't like him anymore, because it's a complicated and intense relationship. Because the relationship is so potent, dropping it and finding someone else is actually a lot harder than people imagine. You really do have to save your energy and invest it in your new relationship, get that going before you say "sayonara" to your last person. Sometimes you don't get to see a patient you've taken care of for years because the insurance plan changed for an arbitrary reason, or she moves away; that's hard, because we get very attached, too.

What do you look for in a doctor? What kind of doctors do you look for? You tell me, what do you look for in a doctor? Compassion. Communication. Expertise. They'll talk to you. They take you seriously. They don't talk over you. They'll return your phone calls. They listen. I like it when a doctor also gives a little touch, a little pat on the back. I think that's an important way to express from one person to the other that they care about you.

Other things? Accessibility, absolutely key. Another thing I think that's really critical, and I think when you hear this you'll probably agree, it's really important to go to a doctor who really likes being a doctor, who really loves what he/she does. Have any of you worked for a doctor who

...it's really important to go to a doctor who really likes being a doctor, who really loves what he/she does.

doesn't like what he/she does? That's bad. That feels really bad. If you can go to a doctor who really likes being a doctor, who really loves what he/she does, that has a contagious energy. The whole staff feels much more enrolled. The whole team works much better under those circumstances. Everyone can get into the work that they're doing. The doctor is more likely to pick up the phone and go out of their way, take the extra time with you. That's so much of what you want. A doctor who really loves what he or she does is more likely to be excited by the new advances and talk about them, rather than be threatened by them and sort of dismiss the conversation.

I find that if I have a doctor who I really like and who's taking care of me, who's accessible, I can trust, who listens, who's there for me — whoa — that is great, and I thank him or her for the privilege of having such a person in my life.

I just want to share a quick story with you. Up until about ten years ago, I was taking care of men with prostate cancer as well as women with breast cancer. I had this guy I was taking care of, and he was a man of very few words. I would say to him, "Mr. Johnson, how was the Eagle's game?" "Fine." I was trying to get to know him a little bit. He was under treatment with me for eight weeks. "How was Thanksgiving?" "Good." "Great! Were the kids home this weekend?" "Yes." So at the very end, it was the end of treatment, I thanked him for the privilege and the honor of taking care of him, and I gave him a hug, which I do for all my patients. He was really embarrassed. He knew it was coming because he saw me do it to other patients. Still, as soon as I let him go, he ran away. I went in the room with another patient, and all of a sudden I heard this music coming down the hallway. I opened the door and there he was. He was a Philadelphia Mummer, all dressed up in a costume, and came back playing the accordion to say thank you to me and my staff; that was truly an honor.

It's such an honor to be given the responsibility and the trust of somebody else who puts their life in your hands. So whatever we can do working as a team to make this relationship the best one it can be, as a doctor, and as a nurse, that's really the best.

I think that the doctor/patient/nurse relationship really is a sacred, important relationship. In fact, I can really think of no other relationship that is more important than this. It's such an honor to be given the responsibility and the trust of somebody else who puts their life in your hands. So whatever we can do working as a team to make this relationship the best one it can be, as a doctor, and as a nurse, that's really the best. When I'm in my doctor role, when the patients let me know who they are, how they like to be taken care of, what's on their mind, who's on their team, who are their family members - then, I can do a much better job and so can you. Patients need to let us know how best to help them. Thank you very much. I thank you for all the amazing work you do every day and every night.

# Exploring Informational Needs

Patient education has always been an integral part of the nurse's role. The technological age allows patients access to information that was not possible even a decade ago. The burden of ensuring that patients and family members seek information from reliable sources and that their informational needs are being met continues to increase. The availability of the Internet and multi-media approaches for patient education expands the opportunity for patients to maintain increased control over the amount of information they pursue. Allowing or encouraging patients to seek information in sources aimed at their specific disease state or education level and at their own pace may reduce the frustration of information overload. However, patients may also realize that it is impossible to master all of the information available and experience feelings of lost control over decision-making.

As with all aspects of nursing care, determining a patient's or family member's informational needs during adjuvant therapy for breast cancer must start with an accurate assessment of the individual's education, culture, and learning style. Many studies have been done to help quantify these variables (Harris, 1998). In one study, ideas about nurse-patient education were confirmed utilizing focus groups, with some intriguing results (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004). For example, the study confirmed the concept that **informational needs** vary over time and vary from patient to patient based on factors such as education, fear, and personality

traits. The researchers also found that many patients reported experiencing more distress related to side effects that they were unprepared to face rather than those side effects that they expected or were prepared to experience (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004).

Studies examining informational needs at the time of cancer treatment reveal that patients most often seek details regarding the treatment, the expected side effects, and management techniques. Equally important was information about how the treatment would directly affect their families, work, and finances. These studies also confirm that the mere provision of written material by staff is insufficient (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004; Sainio & Eriksson, 2003). One study involving women undergoing chemotherapy for breast cancer demonstrated that audiotapes were an effective teaching tool and could prove to be cost-effective resources for patients and family members (Williams & Schreier, 2004). These results reinforce the importance of providing accurate, timely, and appropriate education utilizing resources that are individualized, easy to understand, and readily available.

Patients also reported that other patients were helpful sources of information (Sainio & Eriksson, 2003). While support groups, waiting rooms, and clinic environments all lend themselves to a unique and important bonding for cancer patients, healthcare professionals may worry that shared information may confuse patients as they compare disease status, treatment regimens, or side effects. For example, a woman with in situ disease of the breast may make the erroneous assumption that she will face chemotherapy as stories are shared in the waiting room.

For women in the adjuvant breast cancer setting, the treatment pursued and the informational needs identified will most likely stem from their experiences with initial treatment. Understanding how a woman approached treatment decision making, how she coped with the initial treatment, and how she and her family met the role-change challenges will help the nurse identify gaps in the patient's knowledge of her disease. Subsequently, the nurse can identify appropriate strategies to support future teaching and decision-making.

## Points for Group Discussion:

- How has the process of patient education been influenced by the Internet and multi-media? How have nurses faced these challenges? What new tools or resources have been particularly helpful when teaching patients?
- How can nurses recognize when their patients are experiencing "information overload," and how can patient teaching be modified in those situations?

# Family Communication and Nursing Interventions

Spouses and other family members obviously play an important role in gathering and assimilating information and providing emotional support during cancer treatment. In their work examining family conversations, Duhamel and Dupuis (2004) explored four concepts that must be included in family communication: existence, experience, expertise, and maintaining hope. Reviewing these concepts will allow nurses to recognize nurse-specific interventions that will enhance patient and family education and coping.

Because family members sometimes feel ignored as healthcare providers focus on the patient's response to treatment and side effect management, the art of evaluating family function and existence is challenging. Family members may feel "lost" in their attempts to adapt to the multiple difficulties diagnosis and treatment create for the family. A nurse's acknowledgement that cancer is a "family affair" is an important step in including family members and encouraging their involvement.

Inviting patients and family members to share stories of their disease and experiences not only increases the nurse's ability to individualize care and provide emotional support to the family, but it also allows the story-tellers to clarify their thoughts and feelings. However, in a healthcare environment riddled with increasing demands on decreasing time, nurses may not feel prepared to encourage story telling. Barriers to effective listening include: 1) a focus on managing physical symptoms, 2) a hesitancy to begin conversations about concerns that the nurse feels inadequate to address, or 3) a fear of promoting emotional dependence on the staff. However, if nurses provide these opportunities, family members can share their concerns, recognize ways to better support and help one another, and improve family coping (Duhamel & Dupuis, 2004).

By identifying and acknowledging strengths or abilities of family members, the nurse promotes confidence and reinforces the family's ability to provide supportive care and maintain hope. Examples include acknowledging and

answering pertinent questions, encouraging and recognizing sources of support, and expressing appreciation for efforts made by family members and significant others (Duhamel & Dupuis, 2004). These actions can also help reduce feelings of depression or hopelessness as treatment problems arise. Preservation of hope, a long recognized "ingredient" for healthy adaptation to cancer treatment and survival, is promoted. Hope brings meaning, motivation, and guidance to face daily activities or cope with fear. Hope can spring from many sources, but is also re-enforced by trust. Optimizing communication is one way that nurses can promote that trust.

## Nursing Implications- Patient Education & Family Communication

- Patients are often seeking details of how cancer will affect them, including work, financial, and physical demands of treatment and anticipated changes in their abilities.
- Patients report being more able to effectively cope with side effects that are expected than those for which they feel unprepared.
- Acknowledge that cancer is a "family-affair."
- Encourage story telling for patients and family members to help promote open communication, trust, and intra-family support.
- Identify and acknowledge family strengths and abilities.

# Patient Satisfaction and Decision Making

**M**easuring patient satisfaction as an outcome of quality care has been an important part of both hospital and hospital-based programs for many years because of Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requirements. However, tools such as the Pres-Ganey instruments used to measure patient satisfaction are not nurse-specific and give equal weight to all service departments (Yellen, 2003). Furthermore, the data cannot be extrapolated to non-hospital-based environments. Nevertheless, data gathered can still provide important information that nurses should consider such as the effects of age, gender, culture, and other factors on patient satisfaction.

Because the oncology literature focusing on patient satisfaction is limited, it may also be important to review results from patient satisfaction studies in non-oncology settings. Obviously this data cannot be extrapolated, but results may help guide oncology-related studies. For example, Yellen (2003) noted that the highest correlation

with patient satisfaction in an ambulatory surgical center was communication by the nurse, reinforcing the belief that effective nursing communication and teaching greatly affect optimal care. Results showed that younger patients were more frustrated by the amount of time required to have their individual needs met than were older patients; males were more likely to report low satisfaction with their pain control; and cultural differences related to expressions of pain between Hispanic and non-Hispanic patient populations were pronounced (Yellen, 2003).

An appreciation of a woman's learning style, desire for empowerment, and satisfaction with side-effect management will also help prepare the nurse to further enhance patient education and decision making. Sepucha, Belkora, Aviv, Mutchnick, and Esserman (2003) designed a template for breast cancer patients facing surgical decisions. This concept has been adapted in Table II for use in helping counsel a woman through the decision-making process involved in adjuvant breast cancer care. As nurses help accommodate patient preferences and involvement in decisions, additional effective tools that help engage patients in treatment decisions are needed.

A patient's sense of control over decisions has also been documented as a critical component of satisfactory end-of-life care and is recognized as an important component of breast cancer care throughout treatment (Murray, 2004; Sepucha & Belkora, Aviv, Mutchnick, & Esserman, 2003). Barnes concluded, "What the patients considered to be most important was the relationship that develops among the patient, the family and the health care provider. The degree to which the nurse knew the patient as a person was especially important. What patients often sought was not more information or longer clinic visits but a more personal connection between them and the nurse" (Barnes, Davis, Moran, Portillo, & Koenig, 1998, p. 421).

## Nursing Implications – Patient Satisfaction

- Research is needed to further clarify patient satisfaction in oncology care settings.
- Helping the patient achieve a sense of control is an important part of breast cancer care.
- Decision templates or other tools may be developed to help patients consider various treatment options.
- A personal connection with the patient is a critical component to optimizing patient satisfaction.

**Table 2. Decision Making Template for Adjuvant Breast Cancer Care**

FACTORS	TOPICS	EXAMPLE PROMPTS
<b>Learning preferences</b>	Goals	“If decisions need to be made, how much control do you like to have?”
	Learning Style	“Who are the important people in your life who are usually part of your decision making?”
<b>Testing and prognosis</b>	Testing	“What is your typical reaction to the routine tests that are planned to follow your cancer? Do they help you feel reassured, or do they increase your anxiety?”
	Prognosis	“Do you want specific information about how different treatment options affect statistical prognosis?”
<b>Available choices</b>	Treatment Options	“Can you explain the treatment options that have been outlined in your own words? What questions do you have about these options?”
	Complementary Therapy	“Tell me about any complementary therapies you are using or considering.”
<b>Implications</b>	Side Effects	“Tell me what you understand about potential side effects for each treatment option.”
	Ranking	“How do the risks and benefits of each option compare for you?” “Are you favoring a particular treatment at this point? Explain your reasoning.”
<b>Values</b>	Risk/Benefit	“What benefits of therapy are most important to you?” “What risks are worth considering to obtain your desired benefit?” “Do you have specific fears or hopes related to the treatment options?”
<b>Action to be taken</b>	Making a Choice	“Do you feel confident about the decision you have made?” “Do you have any unresolved questions?” “What steps do you plan to take to begin the treatment process?”
	Resources	“What resources can you identify that will help you proceed with treatment?”

*Note:* Adapted from Sepucha, Belkora, Aviv, Mutchnick, & Esserman, 2003.

Based on questions and answers during an OES ancillary event, “Listen Up: Examining Communication and Optimizing Extended Adjuvant Breast Cancer Care,” at the 30th Annual ONS Congress, Orlando, FL.

# A Dialogue to Remember

**Some of the most common questions patients ask relate to the issue of recurrence: “I’m afraid that it’s going to come back. I finished all my treatment. I’m through with surgery. I’m off tamoxifen. I’m not going to see you anymore. Who’s going to do follow-up visits? What am I going to do if it recurs? What kind of treatment can I have if the cancer comes back? I can’t have surgery again; you’ve already done that. You’ve already given me as much radiation as I can have. I mean, what can I do?”**

**Marisa Weiss, MD:** Well, it’s a fascinating question. I think that one of the things that we as human beings really get stuck on is how to ask a question that we really don’t want to have answered. It’s unusual for a patient to come up and say, “You know what, today I’d like to talk about the fear that I have about recurrence. Could we schedule that conversation? Can we make it a half an hour appointment?” Usually, it doesn’t come out that way. Usually, they’re hanging around a counter, they’re at your desk, and they’re going, “Yeah, you know, my daughter is getting married a year from now.” You’re saying, “Wow, that’s great, really great!” Then they say, “I’m going to miss you guys when treatment is over.” We say, “Oh, we’re really going to miss you. You’ve got to come back and say hello. When you stop in for your follow-up visit, make sure you say hello to everybody.”

Even though they can’t state it, basically, what they’re saying is that they’ve come to really depend on you and seeing you is therapeutic and reassuring, and it’s hard for them to give that up. That’s medicine at its best that you can’t buy in a bottle. It’s what you as nurses give to the patients that gives them so much comfort and reassurance that they can go out on their own and keep walking. But patients definitely are going to express to you - and you know this better than I do - how many different ways they can express the fact that they’re scared to death about recurrence.

Simply acknowledging that fear of recurrence is an absolutely normal concern is the first important step. Recognizing and confirming for patients that, as hard as it is to go through those surgeries, and the chemotherapy, and the radiation, the fact is that it’s also reassuring and therapeutic. I say to patients, “Look, you have adapted so well to this difficult life of going through this treatment, and it’s hard to all of a sudden adjust to the life beyond treatment. You want to celebrate it. And everyone around you wants you to be back to normal, and you want you to be back to normal. But it’s not going to happen so fast, because you’ve changed through this whole process. Be reassured, knowing that we are here for you, that you know how to reach us. We’re going to be seeing you on a regular basis. In addition, we’re going to do tests along the way, such as mammography, ultrasound, MRI scanning and blood work.” Encourage patients to share their concerns.

When treatment is finished, I think it’s important to say to people, “You’ve got to stop and give yourself credit for how much you’ve dragged yourself through; that you really have gotten the best of the treatment today, and you did everything you could that was reasonable.”

**What are the recurrence rates and facts? What can be done to reduce the risks? Will women who have completed therapy really continue with additional adjuvant therapy after five years of tamoxifen?**

**Marisa Weiss, MD:** The fact is that any woman who has had breast cancer could experience a recurrence years down the line. The period people primarily focus on is the first five years. They're saying, "Well, if I can just get to the next year, the next year." It is an important milestone, if you go past the first five years, your risk of recurrence is lower, but it's still there.

African American women tend to get hit harder by breast cancer. They get hit at a younger age. There's less early detection. Therefore they're more likely to present with later stages of disease. The quality of their care probably is not as good as it is for white women. They're also much less likely to ask questions. There are people that we take care of who don't have the confidence, the skills, or the belief that they're entitled to the doctor's time. There may be a mistrust that's sort of culturally present, or just a feeling that the doctor doesn't care about them. We really need to understand how different people express themselves.

It is important to reassure patients that we're following them carefully over time. If they are women who are hormone receptor positive, either estrogen or progesterone receptor positive, that indicates that a woman could benefit and have a reduction in her risk of recurrence if she were to take hormonal therapy such as tamoxifen for pre- and post-menopausal women, or an aromatase inhibitor if the woman is post-menopausal. Taking that pill everyday is a source of reassurance. On the other hand, there are some studies about how many people actually take the pill everyday. A lot of women stop taking daily treatment for a variety of reasons. It's like any illness. Even people who have had a heart attack, high blood pressure, or high cholesterol, believe it or not, only about a third of those people really stick with their medicines, even though they've had a serious complication from those problems. I believe it's the human-to-human contact that makes it stick. After all, if you don't believe in what you're being told to do, you're not going to do it.

**What about patient education? How can we help women make the decisions they face throughout the breast cancer trajectory? Is there a certain type of support that best meets the educational and support needs women with breast cancer experience?**

**Marisa Weiss, MD:** There's an interesting study completed at Harvard. Exit interviews were conducted after a doctor/patient visit. They asked the patient, "How much of what that doctor just said do you remember?" The patient said, "About 15 percent." They said to the doctor, "How much of that conversation do you think that patient got from what you said?" The doctor answered, "About 85 percent."

I think that when women make decisions, it takes time. Women need to process the information before they can make a decision. If the woman is rushed into something that she doesn't understand or by someone she doesn't know, she's probably not going to do it. We know that patients are much more likely to continue with treatment that's going to help them if someone takes the time to explain it. It might not be just once; several patient education sessions may be needed.

We need to recognize that if you go into medicine as a nurse or as a doctor, you are basically making a commitment to being a student forever. It is just true. Maybe you didn't think of that when you went in, but the field of breast cancer is moving ahead very quickly, and you want to be able to get that information when it is available. Thank goodness that progress is happening, but it is frustrating when time is limited for the patient to really discuss all of the issues.

I realized in starting breastcancer.org six years ago that women have questions that hit once the doctor's office is closed, through the day, through the night, and they don't know what to do. They try to make a decision, or their daughter in California says, "You're going to have what tomorrow? When do you get your first chemo? Are you going to need me to be there? Are you going to be able to drive yourself home?" There are so many questions that women have. In starting breastcancer.org and growing it over these years, we really wanted to give women a place to go to get the best medical information whenever it hits. I hope you are using it yourselves, and directing patients

there so that their questions can be answered. I do think when it comes to living with uncertainty, living with a fear of recurrence, there are some things you can help them resolve, and other's you can't.

One thing is giving people answers to questions where the answers exist. Acknowledging that it's normal to be fearful of something that's scary - cancer is a scary thing - but it's the anxiety on top of that fear that can go so far out of control, and that is something that we can work on together with our patients. The support group; the one-on-one; writing down their concerns (that can be very therapeutic); the anti-anxiety medications, even for a short period of time; individual counseling; meditation; visualization; biofeedback; acupuncture. Patients also get a lot of support and encouragement from other patients as well.

### Do you have any specific suggestions or tips on communication?

**Marisa Weiss, MD:** When I first meet someone, I say to them, "Tell me what your understanding is of your situation, and how can I be most helpful to you?" Then, I stop, and I listen. I quickly find out what's on their mind; what kind of words they use; what they're worried about; who they're thinking about, and then they tell me how I could be most helpful to them. By finding out right up front how to do a better job, it takes less time at the end of that meeting. I've done a better job, and she feels better taken care of. Her feeling better, feeling that she's had better care, is what it's all about.

### Points for Group Discussion:

- Does your care setting lend itself to the use of any decision trees? How could nurses help develop such tools to support patient empowerment? What other methods are used to help empower patients?
- Discuss how communication between nurses, physicians, and patients could be improved within your setting.

Interestingly, as women we're always blaming ourselves for what happens. Many times people are feeling very guilty about having a diagnosis because they think that there was something that they did that they shouldn't have done that made this happen. I say to people, "Look, I know you're banging your head against the wall wondering what you did that made this happen. Please stop now because you're going to get a huge headache, and it's not going to help us get through this. What we need to really focus on now is how to help you do whatever is reasonable to get beyond this and hopefully never see it again, but it's going to take a team effort and time."

There are so many wonderful moments that you can have an impact on the care of a patient and on the family. We all hope, as years go by, that we'll come up with a cure for breast cancer, and help make sure that whatever therapeutic measures we have between now and then get to as many women as possible so they all get the benefit.

## Conclusions

Over the past three decades, the management of early breast cancer has seen dramatic improvement due to earlier detection and new therapeutic strategies. Women now have the option of further reducing their risk of recurrence once they have completed tamoxifen therapy, and aromatase inhibitors are proving their clinical benefit in early and extended adjuvant settings. Questions still remain about the optimal duration of treatment, the optimal sequencing of hormonal agents, the role of combination treatment, and the comparative efficacy of the medications in this class of agents.

Faced with the challenge of remaining abreast of changing treatments, nurses must continue to focus on patient education and family support as critical components of their role. Assessing the informational needs of patients and family members, encouraging their involvement and exploration of resources and support, and providing appropriate resources and information will optimize communication, care, and patient satisfaction.

## Patient and Caregiver Resources

American Cancer Society: provides professional and patient related education and programs including “Look Good Feel Better.” [www.cancer.org](http://www.cancer.org); **1-800-ACS-2345**

Breastcancer.org: provides up-to-date medical information about breast cancer. [www.breastcancer.org](http://www.breastcancer.org)

Cancer Care: provides free professional counseling, support groups, and education. [www.cancercares.org](http://www.cancercares.org)

Cancer Hope Network: offers free one-on-one support to cancer patients undergoing treatment. [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

Lance Armstrong Foundation: provides practical information to live strong. [www.livestrong.org](http://www.livestrong.org)

National Breast Cancer Coalition: organization dedicated to ending breast cancer through action and advocacy. [www.stop-breastcancer.org](http://www.stop-breastcancer.org)

National Cancer Institute: provides cancer information, education, and materials. [www.cancer.gov](http://www.cancer.gov); **(CIS) 1-800-4-CANCER**

National Coalition for Cancer Survivorship: advocates for quality cancer care and empowers survivors. [www.canceradvocacy.org](http://www.canceradvocacy.org)

National Lymphedema Network, Inc.: supports patients with lymphedema with counseling and referrals to treatment centers. [www.lymphnet.org](http://www.lymphnet.org)

Oncology Nursing Society Patient Education, Cancer Treatment: [www.ons.org](http://www.ons.org) or link directly to hormonal therapy in breast cancer audio and slide presentations at [www.healthtalk.com/breastcancer/programs/2\\_364/index.cfm](http://www.healthtalk.com/breastcancer/programs/2_364/index.cfm)

Sisters Network, Inc.: African-American breast cancer survivorship organization. [www.sistersnetworkinc.org](http://www.sistersnetworkinc.org)

The Susan G. Komen Breast Cancer Foundation: dedicated to eradicating breast cancer by advancing research, education, screening, and treatment. [www.komen.org](http://www.komen.org); **1-800-I'M AWARE (1-800-462-9273)**

Y-Me National Breast Cancer Organization: provides support groups, wigs, and prostheses to women with limited resources. [www.y-me.org](http://www.y-me.org); **1-800-221-2141**

## Glossary

**Adjuvant therapy** – treatment provided after primary or curative therapy in an attempt to reduce recurrence

**Aromatase** – an enzyme necessary for the synthesis of estrogen from androgens

**Aromatase inhibitor** – a class of agents that block the enzyme aromatase, thereby inhibiting estrogen synthesis

**Estrogen receptor** – a receptor located on tumor cell membranes that is stimulated in the presence of estrogen and stimulates tumor growth

**Estrogen synthesis** – the normal process of creating estrogen by combining androgen hormones with the enzyme aromatase

**Extended adjuvant therapy** – continuing treatment through the use of an aromatase inhibitor after completing 5 years of tamoxifen

**Hormone-receptor-positive tumor** – tumor cells that have membrane receptors for estrogen or progesterone; stimulated in the presence of those hormones and identifiable by laboratory study as hormone-receptor-positive (HR+)

**Hormone-receptor-negative tumor** – tumor cells that do not have membrane receptors for estrogen or progesterone; not stimulated in the presence of those hormones and identified as hormone-receptor negative (HR-)

**Informational needs** – the learning needs identified for a

particular patient. These may be related to concrete information, emotional or coping support, resource identification, or other areas requiring information.

**Micrometastasis** – metastatic deposits that are too small to be clinically identified even by microscopic examination of the tissue field

**Osteopenia** – bone loss defined on bone mineral density study as being between 1 and 2.5 standard deviations less than normal

**Osteoporosis** – severe bone loss defined on bone mineral density study as being more than 2.5 standard deviations less than normal and placing the patient at an increased risk for fracture

**Selective estrogen receptor modulator (SERM)** – an agent that blocks the estrogen receptor on tumor cells. Tamoxifen is the primary example of a selective estrogen receptor modulator.

**Tamoxifen** – a selective estrogen receptor modulator that blocks the hormone receptor sites on tumor cells thereby limiting tumor growth

### Medications mentioned:

Anastrozole (Arimidex®, AstraZeneca, Boston, MA)

Exemestane (Aromasin®, Pharmacia & Upjohn/Pfizer, New York, NY)

Letrozole (Femara®, Novartis, East Hanover, NJ)

Tamoxifen (Novaldex®, AstraZeneca, Boston, MA)

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# Continuing Education Post-Test

1. Which of the following individuals would be most appropriate for extended adjuvant therapy with an aromatase inhibitor?
  - a. 69-year-old woman who completed 5 years of tamoxifen
  - b. 38-year-old woman who had lumpectomy and radiation
  - c. 42-year-old woman scheduled for mastectomy
  - d. 74-year-old woman who has hepatic dysfunction after chemotherapy
2. Which of the following statements is true regarding the interaction of hormones, hormonal agents, and breast cancer?
  - a. All breast tumors are affected by changes in the hormonal environment.
  - b. Tamoxifen works by blocking the estrogen receptor at tumor sites.
  - c. Aromatase inhibitors prevent the release of androgens.
  - d. Post-menopausal women are not good candidates for hormonal therapy.
3. In educating a woman about to begin therapy with an aromatase inhibitor, the nurse would make which of the following recommendations for side effect management?
  - a. "You should have a baseline assessment of your bone density."
  - b. "It will be important for you to increase your intake of red meat."
  - c. "You will need to use effective birth control throughout your treatment."
  - d. "This medication may cause hair loss."
4. Which of the following statements is most associated with the MA-17 trial results?
  - a. This open-label study has yet to be published.
  - b. Patients were randomized to placebo or an aromatase inhibitor after completing nearly five years of tamoxifen.
  - c. This study involved a cross-over to help determine the effectiveness of an aromatase inhibitor after a 2-3 year course of tamoxifen.
  - d. Over 9000 women participated to compare an aromatase inhibitor, tamoxifen, or a combination therapy.
5. A patient is raising concerns about hot flashes. The nurse would base advice on his/her understanding that:
  - a. Dietary changes are not effective in the management of hot flashes.
  - b. Hormonal agents would be contraindicated in women receiving tamoxifen or aromatase inhibitor therapy.
  - c. Research on the management of hot flashes for all post-menopausal women can readily be extrapolated to the breast cancer population.
  - d. Behavioral interventions have no proven role in hot flash management.
6. Which of the following accurately reflects a common emotional reaction women have to the completion of therapy?
  - a. Fear of long term side-effects
  - b. Frustration with insurance coverage for experimental therapy
  - c. Frustration with multiple decisions
  - d. Fear of recurrence
7. Which of the following statements best reflects the knowledge gained by studying patient's information needs?
  - a. Patients need timely information that they can understand.
  - b. Patient education brochures are sufficient for most people.
  - c. A majority of patients are intimidated by technology.
  - d. Patients rarely seek information from each other.
8. Common informational needs for patients with breast cancer may include:
  - a. Identifying morbidity and mortality rates
  - b. Listing celebrities who have overcome breast cancer
  - c. Giving the family members a tour of the chemotherapy clinic
  - d. Providing details regarding the impact of cancer and cancer treatment
9. Which of the following factors is recognized as having a major impact on patient satisfaction with teaching?
  - a. The nurse's knowledge of the topic
  - b. The nurse's ability to listen effectively
  - c. The nurse's clinical competence
  - d. The nurse's clinical experience
10. Research has suggested that the side effects most distressing to patients are those that they were least prepared to experience.
  - a. True
  - b. False



# Post-Test Answer Sheet and Evaluation

Listen Up! Examining Communication and Optimizing Extended Adjuvant Breast Cancer Care

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Please circle the letter corresponding to your answer:

1.     A     B     C     D
2.     A     B     C     D
3.     A     B     C     D
4.     A     B     C     D
5.     A     B     C     D
6.     A     B     C     D
7.     A     B     C     D
8.     A     B     C     D
9.     A     B     C     D
10.    A     B

To receive continuing education credits for this educational monograph, you must successfully complete the post-test and submit a completed evaluation form.

**CE for this monograph expires  
August 1, 2007.**

## Evaluation Form

To assist us in evaluating the effectiveness of the educational design of this monograph and in making recommendations for future CE activities, please complete the evaluation form by circling the appropriate rating.

Key: 1 = Poor 2 = Fair 3 = Satisfactory 4 = Excellent

**How relevant were the objectives to the CE activity's purpose/goals?**

The overall educational objective is to examine communication as a key component to patient education and optimal care for women receiving extended adjuvant breast cancer care.

1     2     3     4

**To what degree did you meet the following objectives?**

Summarize current adjuvant hormonal agents and the research that is influencing treatment options.

1     2     3     4

Identify common educational needs related to breast cancer care, and nursing actions that can optimize patient teaching.

1     2     3     4

List two factors that influence patient satisfaction with communication and teaching.

1     2     3     4

**Based on previous experience and knowledge, the level of information in this monograph was:**

1 = Too basic     2 = Appropriate     3 = Too complex

How long did it take you to complete this activity? \_\_\_\_\_ minutes

**Why did you participate in this activity?**

- \_\_\_ a. Amount of continuing education credit hours
- \_\_\_ b. Importance of topic
- \_\_\_ c. Quality of faculty
- \_\_\_ d. Other: \_\_\_\_\_

**How did you obtain this monograph? (Check all that apply)**

- \_\_\_ a. Friend or colleague     \_\_\_ d. Conference
- \_\_\_ b. ONS website     \_\_\_ e. Free subscription
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Will this monograph assist you in providing effective patient care?

\_\_\_ Yes    \_\_\_ No

Was this monograph free of commercial bias? \_\_\_ Yes    \_\_\_ No

If not, why not? \_\_\_\_\_

How will you modify your practice as a result of this monograph?

\_\_\_\_\_

What topics would you like to see in the future?

\_\_\_\_\_

Comments and suggestions for improvements

\_\_\_\_\_

