



Questions about side effects? Your patients' perhaps not so surprising source for answers

Bette Weinstein Kaplan

When your breast cancer patients have difficulty tolerating their adjuvant therapy, do they complain to you or another member of your team about the side effects of the aromatase inhibitors (AIs) they are taking? Not so much, according to a newly published study. Many of these patients take their discussions to another place—the Internet.

When hormone receptor-positive breast cancer is diagnosed in a postmenopausal woman, there is a good chance her therapy will include an aromatase inhibitor because these medications are most commonly prescribed to prevent recurrence. Although aromatase inhibitors are effective, they are not without side effects, most notably joint and musculoskeletal pain. Given that a large percentage of patients will have difficulty with the side effects of these drugs, researchers from the Perelman School of Medicine at the University of Pennsylvania, in Philadelphia, undertook a study to ascertain where these women turn when they have questions.

There are now 2.5 million breast cancer survivors in the United States, comprising the largest group of cancer survivors in this country.¹ With so many of them taking aromatase inhibitors, Jun J. Mao, MD, MSCE, assistant professor of Family Medicine and Community Health at Perelman and director of the Integrative Oncology program at the University of

Pennsylvania's Abramson Cancer Center, also in Philadelphia, wondered how they cope. He initiated the study to find out how patients were using social media to discuss their health care concerns, with a particular emphasis on AI-related arthralgia in women undergoing treatment for breast cancer, and if Internet resources help these survivors manage the drug's troublesome symptoms.¹

Patients who posted discussed how they came to identify with their disease.

MUSCULOSKELETAL SYMPTOMS TOP THE LIST

Although the incidence of AI-associated musculoskeletal symptoms is unclear, they are more prevalent with AI use than with tamoxifen (Soltamox, generics), and can be a common reason for patients to discontinue their AI medication. The mechanisms of AI-associated musculoskeletal symptoms are not clear. Scientists do know that estrogen deficiency causes bone loss, which can manifest as arthralgia.² The CIRAS study included 48 postmenopausal women with stage I-III breast cancer and hand pain. Most of the participants had been taking AIs

for more than 6 months. The researchers could not find an association between the presence of AI-associated musculoskeletal pain and exposure to other chemotherapy or medication, nor could they find evidence of inflammatory arthritis to explain the hand pain.³

According to the University of Pennsylvania group, previous studies have shown that almost 50% of breast cancer survivors taking AIs do not complete their course of treatment. Furthermore, those women who do not take the medication as prescribed or who stop taking it altogether are more likely to die from their breast cancer and other causes.¹ Message boards and other social media may play a significant role in whether these patients continue their medication.

For this study, Mao and senior author John Holmes, PhD, associate professor of Medical Informatics in Epidemiology at Perelman, analyzed 25,256 pertinent message board posts. They reviewed 12 popular Web sites, including WebMD, breastcancer.org, Susan G. Komen for the Cure, and Oprah, and found that 18% of people who posted mentioned having at least one AI-related side effect. The symptoms that patients cited most often were joint and musculoskeletal pain, followed by hot flashes, night sweats, osteoporosis, and weight gain.

Among the women who posted on these boards, 28% wrote that they

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were changing to a different aromatase inhibitor. Almost 13% wrote that they were discontinuing the drug they were on and had no plans to take a different drug. Severe joint pain was the reason patients cited most often for discontinuing therapy. Almost 20% of message board users posted to request advice on coping with their joint pain. Nearly 30% of message board users actually gave advice and tips.

GOOD ADVICE OFFERED, BUT FEW URGED STAYING ON AIs

The advice given on Internet message boards included trying to exercise to relieve symptoms or prevent the pain from becoming more severe, taking a prescription or OTC analgesic, and trying a supplement such as glucosamine

or chondroitin. Although 27% of the respondents who gave advice suggested asking your physician for help in coping with the arthralgia, only 8% of respondents who provided advice actually urged those who were asking to stay on an aromatase inhibitor.

The University of Pennsylvania group found that many patients who posted on the Internet discussed how they came to identify with their disease or with the painful side effects of their therapy. Message-board participants wrote that the AIs were barely tolerable, but they were continuing the therapy because they were afraid of relapse. One posting said, “The way I look at it, at 53 years old, I was likely to get arthritis anyway, and any discomfort as a result of treatment is well worth

prolonging my life.”¹ Those who gave advice reminded those who sought it that there are many different AIs available, and that patients should stay on the drug for a few months before switching or stopping their medication.

The authors of this study suggest that the Internet offers a wide range of perspectives. Oncology care providers can use its data to help patients make decisions that will improve their quality of life. ■

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REFERENCES

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ONA ASKS ...



Are you concerned about the advice your patients receive through message boards?

Go to OncologyNurseAdvisor.com/message_boards to answer this question in the online version of this article.