

Study of breast cancer message boards finds frequent discussion of drug side effects, discontinuation of therapy

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(Medical Xpress)—In the first study to examine discussion of drug side effects on Internet message boards, researchers from the Perelman School of Medicine at the University of Pennsylvania found that breast cancer survivors taking the commonly prescribed adjuvant therapy known as aromatase inhibitors (AIs) often detailed in these forums troublesome symptoms resulting from the drugs, and they were apt to report discontinuing the treatment or switching to a different drug in the same class. The findings are published online this week in the journal *Pharmacoepidemiology and Drug Safety*. With 2.5 million breast cancer survivors living in the United States today – the largest group of cancer survivors – researchers say the findings have broad implications for physician communication with patients about these issues to help to promote proper adherence and inform patient-to-patient discussion online.

"Both the availability and anonymity provided by message boards – and increasingly, other forms of social media such as [Twitter](#) and [Facebook](#) – offer patients a place to voice concerns and connect with an audience of peers in similar situations. This type of social support can be very valuable to patients who are struggling with side effects like joint pain, and may serve as a forum where they will be encouraged to seek help from their physician," says the study's lead author, Jun J. Mao, MD, MSCE, an assistant professor of [Family Medicine](#) and Community Health, who directs the Integrative Oncology program in Penn's

Abramson Cancer Center. "However, our findings indicate that message board discussion of the side effects of AIs may also have [negative consequences](#) for adherence to therapy, or make patients reluctant to begin taking these drugs at all."

AIs are the most commonly used medications to prevent recurrence among post-[menopausal women](#) with [hormone receptor](#) positive breast cancer, leading to an annual revenue of over \$3.5 billion worldwide. Previous studies have shown that nearly half of women taking AIs do not complete their recommended course of treatment, and that those who stop taking the drugs or don't take them as prescribed have a higher chance of dying of both breast cancer and other causes.

Using both quantitative and qualitative methods, the researchers analyzed 25,256 message board posts related to AIs hosted on 12 popular web sites, including breastcancer.org, Susan G. Komen for the Cure, Oprah.com, and WebMD. They found that more than 18 percent of authors mentioned at least one side effect. Most commonly, patients reported joint and musculoskeletal pain, also known as arthralgia, which was mentioned by about a quarter of those who wrote about side effects; along with hot flashes and night sweats, osteoporosis, and weight gain.

Among authors who wrote about taking AIs, 12.8 percent mentioned discontinuing the drugs with no plans to take another kind, and another 28 percent mentioned switching to a different type of AI. Patients often cited severe joint pain as the reason for their discontinuation of the therapy, which is typically prescribed for several years following active treatment. A qualitative analysis of 1,000 randomly selected posts revealed that 18 percent of messages were from authors seeking advice from other message board users on how to cope with joint pain, and 27.8 percent gave advice, with about a third of those messages including tips for dealing with that side effect. Forty two percent of advice-givers recommended prescription or over-the-counter drugs for pain relief, and

44 percent mentioned herbal or mineral supplements such as glucosamine and chondroitin. Thirty percent of women who gave advice reported using exercise to get relief or prevent pain from worsening. Twenty-seven percent of the advice-givers urged others to seek help from their own physicians, but only 8 percent explicitly urged others to stay on AIs.

Typical responses among those who reported struggling with side effects spoke of a shift in their identity since being diagnosed with cancer, coupled with a profound fear of discontinuing the therapy: "I hurt, ache, swell, pain, shuffle, have significant joint pain, have cognitive issues, and feel like I'm 80 when I'm mid-50's. But I'm also so afraid of the [breast cancer](#) that I shuffle alongside of everyone, like you do." On the other end of the spectrum, some women described feeling that the benefits of the therapy outweighed the risks: "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." Advice-giving messages often included sentiments of hope, including reminders that there are multiple types of AIs that women can try if they have problems, and they underscored the importance of taking the drugs for a few months before making a decision about switching or discontinuing the therapy.

Mao and senior author John Holmes, PhD, associate professor of Medical Informatics in Epidemiology, suggest that their findings reveal that mining social media discussions about health issues may provide novel insights about patient perceptions of drug [side effects](#) and their potential impact on adherence to recommended therapies.

"On the internet, patients come together from a broad swath of geographic areas, from many racial and socioeconomic backgrounds and from treatment in different types of clinical settings," Holmes says. "This range of perspectives would be difficult to capture in a typical clinical trial or survey, and may provide valuable data to guide health

care providers seeking new ways to engage with patients and help them make decisions that will improve their health and provide them with a good quality of life."

Provided by University of Pennsylvania School of Medicine

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