Chemo Brain, Antiestrogens, and Me

Catherine C. Simmons, RN, MSN, CNS, OCN®

I am an oncology clinical nurse specialist who was diagnosed and treated for breast cancer in 2001. I attended a survivorship workshop in Boston in 2007 where one of the guest speakers addressed chemo brain, which is broadly defined as difficulty with cognitive functions such as memory and maintaining focus or attention as a result of the side effects of chemotherapy (Staat & Segatore, 2005). The part of the presentation that caught my attention was when the speaker said, “We have known this was happening for years, but...”

I was so surprised at the first part of that statement that the end did not matter to me. All I could think was, "They knew this was happening for years and nobody told us!" I was screaming inside my head. Did they also know how much anxiety, distress, and personal hardship this created for those of us who experienced it? The speaker went on to say that they had no credible evidence at the time to confirm their incidental findings. The research was in its infancy. That answer just did not seem good enough for me.

Continuing Research

The oncology community needs to understand how important every study is to survivors, even studies with incidental findings related to chemo brain. Healthcare workers who also are cancer survivors are prone to be hypervigilant as we scan the literature and research for any clue that can help us better cope with our disease. Unfortunately, in 2001 and 2002 when the research was first being published, people did not take notice. Therefore, many survivors were not educated about the potential risk of chemo brain.

According to Myers and Teel (2008), 94% of their nurse study group was aware of cognitive impairment when associated with chemotherapy. Sixty-eight percent estimated that 1%–40% of their patients experienced cognitive distress after receiving chemotherapy. Unfortunately, only 38% of the study group assessed patients for cognitive impairment and 44% educated their patients on the distressing symptom.

I am now convinced that traditional chemotherapy drugs are not the only cancer treatment agents that can cause cognitive difficulties. Most of the research to date has been conducted on traditional agents such as high-dose cytosine arabinoside or cytoxan. But what of the adjuvant hormonal agents that are given after chemotherapy? Anecdotally, some women I know who took antiestrogens stopped taking it after a few months because, as one colleague said, “It made me crazy.”

After my primary treatment for breast cancer was completed in 2002, my oncologist prescribed an antiestrogen. A few

My supervisor suggested that I quit the job. I left confused and upset that I could not get a handle on this thing that was happening to me.

Catherine C. Simmons, RN, MSN, CNS, OCN®, is an oncology clinical nurse specialist at the Miriam Hospital in Providence, RI. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Clinical Journal of Oncology Nursing or the Oncology Nursing Society.

Digital Object Identifier: 10.1188/09.CJON.253-254
months later, after returning to work, I started noticing that I was having difficulty focusing and fulfilling my responsibilities at home and at work. I attributed my work difficulties to fatigue and to being out of synch with the routine. However, later in the year, my supervisor suggested that I quit the job because my performance was not up to the standard required of the position. I had not thought it was that bad. I left confused and upset that I could not get a handle on this thing that was happening to me. I redefined the experience as a rough two years and left it at that.

I believed the unpleasantness was behind me when I took a job as a clinical educator in a new facility. However, in 2005, my supervisor took me aside and told me that I had symptoms of adult onset attention deficient hyperactivity disorder (ADHD). I was unable to sit at my desk for long periods of time, I left meetings abruptly without asking to be excused, and I frequently remained stuck in a conversation long after the topic had changed. I was not focused, organized, or productive. It was suggested that I go to employee assistance for counseling. Upset and confused, I followed through with this suggestion but knew it would not be easy to get the answer to this now obvious problem. I called a psychologist for advice. He tested me for ADHD. That test was negative. Now scared and frustrated, I called my oncologist.

I asked myself, “What if my cancer was back or was there something else going on in my head that I needed to be concerned about?” My second thought was, “Could this be due to the antiestrogen?” By now I had read an article by Staat and Segatore (2005) on the chemo brain phenomenon. My oncologist was skeptical that I was suffering from a form of chemo brain from the antiestrogen. I was disappointed at not having an answer. All my other doctors concurred; none thought it was from the chemotherapy or antiestrogens. I could not fight city hall, so off I went for a head computed tomography. No problems were identified, so I was sent for a neuropsychological evaluation. It also was normal. So far I had completed three very extensive, expensive, time-consuming tests that all were negative and I still had no answers.

Searching for Answers

I attended the Oncology Nursing Society’s 30th Annual Congress in Orlando, FL, in 2005 and met a nurse doing a poster session on cognitive difficulties after receiving chemotherapy. I asked her if any evidence showed that antiestrogens caused cognitive difficulties. The answer was “no.” I went to the exhibition hall and asked a pharmaceutical company representative to check a database to see if any record existed of complaints about confusion or lack of focus while on antiestrogens. None were identified.

I called my oncologist when I returned home and discussed the onset of this confusion and how it was not getting any better. Finally, after reviewing all my test results and having no other explanation, my oncologist stopped the antiestrogen and prescribed exemestane (Aromasin®, Pfizer). I could tell a difference within the first month. It was like a veil was lifted off of my eyes. The difference was remarkable. I could focus on conversations, meetings, movies, and the concerns of staff, faculty, students, and my family. I had a strong sense of being productive. My work returned to its previous pre-cancer quality and distinction. My personal life instantly improved. I continued in my job and received excellent work-related reviews from my supervisors for the next three years until I left for my current position.

Clinical Trial

I could not find anything in the literature that identified antiestrogens as a cause of cognitive difficulties. I have, however, found a related clinical trial. The National Institute on Aging (NIA) is conducting a study to assess the effects of nolvadex (Tamoxifen®, AstraZeneca) and raloxifene HCL (Evista®, Eli Lilly & Co., Inc.) on cognitive aging in selected cognitively healthy women (NIA, 2008). The study is examining verbal and non-verbal memory, mood, and other cognitive functions of women older than age 65 taking nolvadex or raloxifene HCL. Additional research is needed in this area.

As oncology nurses, we owe it to our patients to keep up with research on chemo brain and pass on new information. We may be able to give patients some peace of mind by sharing research findings and reassuring them that they are not crazy.